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No. 84-1529

IN THE
SUPREME COURT OF THE UNITED STATES

October Term, 1985

MARGARET M. HECKLER, SECRETARY
OF HEALTH AND HUMAN SERVICES,
Petitioner,

v.

AMERICAN HOSPITAL ASSOCIATION, *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Second Circuit

BRIEF AMICI CURIAE OF THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES; PEOPLE FIRST ORGANIZATIONS OF CALIFORNIA, IOWA, LOUISIANA, MICHIGAN, NEBRASKA, OREGON AND WASHINGTON; PEOPLE FIRST INTERNATIONAL; UNITED TOGETHER ORGANIZATIONS OF ARKANSAS, CALIFORNIA, FLORIDA, IDAHO, KANSAS, MASSACHUSETTS, MINNESOTA, AND MONTANA; SPEAKING FOR OURSELVES OF PENNSYLVANIA; CONSUMER ADVISORY BOARD OF MASSACHUSETTS; SELF-ADVOCATES OF CENTRAL NEW YORK; TEXAS ADVOCATES; WISCONSIN ADVOCATES; DISABLED IN ACTION OF PENNSYLVANIA; DISABLED IN ACTION OF NEW YORK; AND THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS

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S. REP. NO. 160, 94th Cong., 1st Sess. (1975) 23

OTHER AUTHORITIES

I. ABT & F. GARRISON, HISTORY OF PEDIATRICS (1965) .. 15

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Affleck, *Physicians' Attitudes Toward Discretionary Treatment of Down's Syndrome Infants*, 18 MENTAL RETARDATION 79 (1980) 15

AMERICAN ACADEMY OF PEDIATRICS, THE FUTURE OF PEDIATRIC EDUCATION: A REPORT BY THE TASK FORCE ON PEDIATRIC EDUCATION (1978) 17

American Medical Association, Statement of the House of Delegates, Dec. 4, 1973, *reported in* 227 J.A.M.A. 728 (1974) 28

Baker, *Outcome Equality or Equality of Respect*, 131 U. PA. L. REV. 933 (1983) 23

Baldwin, *The Causes, Prevention and Care of Feeble-Minded Children*, in PROCEEDINGS OF THE TEXAS CONFERENCE OF CHARITIES AND CORRECTIONS AT ITS SECOND ANNUAL MEETING 87 (1912) .. 13

V. BARRY, MORAL ASPECTS OF HEALTH CARE (1982) 6

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Burt, *Constitutional Law and the Teaching of Parables*, 93 YALE L. J. 455 (1984) 16

CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, FIRST BIENNIAL REPORT (1905) 12

CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, BIENNIAL REPORT (1916) 14

CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, BIENNIAL REPORT (1918) 14

Chicago Daily News, Nov. 19, 1915, at 3 10

Chicago Tribune, Nov. 17, 1915, at 1 10

TABLE OF AUTHORITIES—*(Continued)*

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Chicago Tribune, Nov. 18, 1915, at 2 10

D. CRANE, THE SANCTITY OF SOCIAL LIFE (1975).. 15, 16, 18

Crile, *The Right to Life*, Medical Tribune, December 19, 1984 16

Columbus (Ohio) Evening Dispatch, Nov. 17, 1915, at 2. 10

Darling, *Parents, Physicans and Spina Bifida*, 7 HASTINGS CTR. REP., Aug., 1977, at 10 ..... 15, 16

Defective Babe Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Country's Good, New York Times, Nov. 18, 1915, at 1 9

Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 N. ENG. J. MED. 890 (1973) 15, 16

J. DUFFY, THE HEALERS (1976) 15

J. P. EDWARDS, WE ARE PEOPLE FIRST: OUR HANDICAPS ARE SECONDARY (1982) 17

FIRST BIENNIAL REPORT OF THE BOARD OF COMMISSIONERS OF NEBRASKA INSTITUTIONS (1915) 12

Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 PEDIATRICS 321 (1981) 29

FOURTH BIENNIAL REPORT OF THE SOUTH DAKOTA COMMISSION FOR SEGREGATION AND CONTROL OF THE FEEBLE-MINDED (1932) 12, 30

FOURTH BIENNIAL REPORT OF THE UTAH STATE TRAINING SCHOOL (1938) 12

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Goldstein, *Medical Care for the Child at Risk*, in W. GAYLIN & R. MACKLIN, WHO SPEAKS FOR THE CHILD 153 (1982) 20

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Gross, *et al.*, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1980) 15, 16, 18

Ingelfinger, *Bedside Ethics for the Hopeless Case*, 289 N. ENG. J. MED. 914 (1973) 29

Karst, *Supreme Court, 1976 Term — Forward: Equal Citizenship Under the Fourteenth Amendment*, 91 HARV. L. REV. 1 (1977) 23

Kennedy, *The Problem of Social Control of the Congenital Defective*, 99 AM. J. PSYCH. 13 (1943) 11

Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Retarded*, 13 MENTAL RETARDATION 10 (1975) 18

S. L. Kuepper, Euthanasia in America, 1890-1960 (Rutgers Univ. diss. 1981) 10

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C. E. KOOP, THE RIGHT TO LIVE, THE RIGHT TO DIE (1980) 6

Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BRIT. MED. J. 201 (1973) 15

Lorber, *Spina Bifida Cystica: Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future*, 47 ARCH. OF DISEASE IN CHILDHOOD 854 (1972) 29

G. FRANK LYDSTON, M.D., DISEASES OF SOCIETY (1906). 11

MENTAL DEFECTIVES IN INDIANA: THIRD REPORT OF THE COMMITTEE ON MENTAL DEFECTIVES (1922) 13

PRESIDENT'S PANEL ON MENTAL RETARDATION, A PROPOSED PROGRAM FOR NATIONAL ACTION (1962) 17

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REPORT OF THE COMMISSION ON SEGREGATION, CARE AND TREATMENT OF FEEBLE-MINDED AND EPILEPTIC PERSONS IN PENNSYLVANIA (1913) 12

Rachels, *Active and Passive Euthanasia*, 292 N. ENG. J. MED. 78 (1975) 28

Randolph, *Consultant's Note*, 10 HOSP. ROUNDS, Sept., 1974, at 23 29

REPORT OF THE RHODE ISLAND SCHOOL FOR THE FEEBLE-MINDED (1910) 12

REPORT OF THE VERMONT SCHOOL FOR THE FEEBLE-MINDED (1916) 12, 13

Report of the Legislative Visiting Committee, WISC. SEN. J. 263 (48th Leg. Sess.) 13

Shaw, *Dilemmas in Informed Consent in Children*, 289 N. ENG. J. MED. 885 (1973) 29

Shaw, *et al.*, *Ethical Issues in Pediatric Surgery*, 60 PEDIATRICS 588 (1977) 6, 15, 16

Shurtleff, *Myelodysplasia: Decision for Death or Disability*, 291 N. ENG. J. MED. 1005 (1974) 30

Shurtleff, *Myelodysplasia: Management and Treatment*, 10 CURR. PROBS. IN PEDIATRICS 1 (1980) 11

Stein, *et al.*, *Selection for Early Treatment in Myelomeningocele: A Retrospective Analysis of Various Selection Procedures*, 54 PEDIATRICS 553 (1974). 29

Randolph, *Surgical Decision—Is There a Choice?* in ROSS CONFERENCE ON PEDIATRIC RESEARCH, ETHICAL DILEMMAS IN CURRENT OBSTETRIC AND NEWBORN CARE 58 (1973) 29

O. TEMKIN, *et al.*, RESPECT FOR LIFE IN MEDICINE, PHILOSOPHY AND THE LAW (1977) 15

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The Right To Kill, TIME, Nov. 18, 1935, at 53 11

Strain, *The Decision to Forego Life Sustaining Treatment for Seriously Ill Newborns*, 72 PEDIATRICS 572 (1983) 18

THIRTEENTH BIENNIAL REPORT OF THE KANSAS SCHOOL FOR FEEBLE-MINDED YOUTH (1906) 13

THIRTY-SIXTH ANNUAL REPORT OF THE INDIANA SCHOOL FOR FEEBLE-MINDED YOUTH (1914) 12

Todres, *et al.*, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977) 15

TWENTY-FIRST BIENNIAL REPORT OF THE KANSAS TRAINING SCHOOL (1922) 14

Wald, *State Intervention on Behalf of 'Neglected' Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975) 16

WEHMAN, COMPETITIVE EMPLOYMENT: NEW HORIZONS FOR THE SEVERELY DISABLED (1981) 16

P. WILLIAMS & B. SHOULTZ, WE CAN SPEAK FOR OURSELVES (1982) 17

WISCONSIN BOARD OF CONTROL, BIENNIAL REPORT (1898) 12

Wolraich & Siperstein, *Assessing Professionals' Prognostic Impressions of Mental Retardation*, 21 MENTAL RETARDATION, Feb., 1983, at 8 17

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ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE SECOND CIRCUIT

BRIEF AMICI CURIAE OF AMERICAN COALITION OF CITIZENS WITH DISABILITIES, *et al.*

INTERESTS OF AMICI CURIAE[1]

Amici are the largest national association and organizations from eighteen states founded by and comprised of persons with lifelong disabilities, in addition to the association of the protection and advocacy systems created by 42 U.S.C. §6012. All are keenly interested in effective civil rights deprivations such as denying handicapped persons medical services normally provided nonhandicapped persons. Many of amici's members lead active, fruitful, enjoyable lives today because as children they received lifesaving medical assistance, against the advice of physicians.

1. All parties have consented to the filing of this brief.

THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES, with eight million members, chiefly adults with longterm, severe handicaps, is the largest organization in the nation devoted to securing the civil rights of people with disabilities. Over 200 organizations in all of the fifty states are constituents of the Coalition, which has participated actively in the formulation of public policy respecting the rights of disabled citizens in the national congress, the executive, and the states, and has been recognized in every forum, as fairly and fully representative of disabled citizens. The formation on July 19, 1974 of the Coalition was evoked by the passage of Section 504. Its constituent organizations were major participants in the political and legislative processes resulting in Section 504 and in each of the enactments related to it. The Coalition was the major political actor in securing regulations to implement Section 504 and its 1974 amendments. The Coalition was one of the amici in *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984), whose majority opinion was viewed by the court below as dispositive of its judgment, but whose dissent by Circuit Judge Winter embraced the argument of several of the amici here.

PEOPLE FIRST ORGANIZATIONS OF CALIFORNIA, IOWA, LOUISIANA, MICHIGAN, NEBRASKA, OREGON and WASHINGTON; PEOPLE FIRST INTERNATIONAL; UNITED TOGETHER ORGANIZATIONS OF ARKANSAS, CALIFORNIA, FLORIDA, IDAHO, KANSAS, MASSACHUSETTS, MINNESOTA and MONTANA; SPEAKING FOR OURSELVES OF PENNSYLVANIA; TEXAS ADVOCATES; WISCONSIN ADVOCATES; and SELF-ADVOCATES OF CENTRAL NEW YORK are organizations established and led by retarded adults, most of whom are severely handicapped and many of whom are former or current residents of public institutions. Their common purpose: to speak for themselves rather than to let others speak for them and to know and exercise their rights as citizens, including the right to live in the community.

DISABLED IN ACTION OF METROPOLITAN NEW YORK and DISABLED IN ACTION OF PENNSYLVANIA were formed for the

purpose of securing full civil rights for all persons with disabilities in such areas as health care. They have been amici in several cases before this Court and DIA of New York was one of the amici in *University Hospital*.

THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS is comprised of the fifty independent State agencies designated by the Governors of the respective States and established pursuant to Section 113 of the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §6012, to protect and advocate disabled persons' rights. Section 504 has been the central, crucial instrument of these systems in their representation of handicapped children denied lifesaving medical assistance, and in attempting to secure the education of medical professionals to the real, and large, capabilities of severely disabled people.

SUMMARY OF ARGUMENT

1. The practice of denying lifesaving medical assistance to disabled children was an integral part of, and its continuing currency is firmly embedded in, the "history of unfair and often grotesque mistreatment" arising from the "prejudice and ignorance" acknowledged in *City of Cleburne, Texas v. Cleburne Living Center*, 105 S.Ct. 3249, 3262 (Stevens, *J.*, joined by Burger, *C.J.*, concurring), 3266 (Marshall, joined by Brennan & Blackmun, *JJ.*, concurring) (1985). The "regime" that permitted the destruction of handicapped people and their segregation from the rest of us for life continues to be expressed in withholding lifesaving medical assistance from children who have lifelong, severe disabilities. In 1915, a lifesaving operation was denied a disabled child because his "partial paralysis and the malformations were so great a bar to happiness or attainment, . . . there was no chance that life would bring this child anything better than an animal existence and imbecility. . . . I believe I have done the child, its parents . . . and the race a favor." Today the practice is justified in the same terms, *e.g.*, handicapped children have "no hope of achieving meaningful 'humanhood'."

2. Section 504 was the keystone of the "distinctive legislation response" invoked in *Cleburne*: a related series of statutes formulated and enacted by the national legislature during three Congresses, 1971-1975. Congress reversed the legacy of mistreatment and required admission of all disabled people — especially severely disabled people — to the benefits of our society. It was "a fairly won political victory." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting). Congress acted to end state-imposed segregation of severely disabled people, to end their isolation and to remove them from the status theretofore imposed upon them as "the expendables." Congress compiled a legislative record of unparalleled completeness on the modern understanding of the great capabilities of severely disabled people for learning, for productive work, for community participation, on modern techniques to support disabled people in the full realization of their capabilities, and on historical and continuing obstacles to achieving them.

The very matter at issue here — part of the "true story of exclusion and inadequate concern" chief sponsor Senator Humphrey said, 118 CONG. REC. 9495 (1972), was set out in the legislative history, *e.g.*: ". . . pediatricians . . . who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents; . . . doctors who urged [parents] to put [their child] in an institution and forget about him. There was so much willingness to eliminate the child, because they did not consider him a productive member of society." 118 CONG. REC. at 9500. The matter here is thus squarely encompassed by Section 504. Using all its powers, Congress in Section 504 opened equal citizenship fully to all severely disabled people. By its plain language and by Congress' richly articulate intention, Section 504 prohibits the denial of lifesaving medical assistance to severely disabled people.

3. Absent enforcement of Section 504, the legacy of "ignorance and prejudice," *Cleburne*, 105 S.Ct. at 3262, continues among medical professionals to work its destructive effect. Enforced, Section 504 calls an *informed* medical profession to itself, to an active respect for the lives of all people including, as the

Congress has directed, people who have lifelong, severe disabilities. "[A] decision not to correct a life-threatening digestive problem because an infant has Downs Syndrome is not a *bona fide* medical judgment." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting).

ARGUMENT

In *Meyer v. Nebraska*, 262 U.S. 390, 401-02 (1923), the Court stated that the historical practice of " 'putt[ting] away . . . the offspring of the inferior, or of the better when they chance to be deformed' " would "do . . . violence to both the letter and the spirit of the Constitution." Three years later counsel for Carrie Buck argued here that sterilization imposed by a State because of her "feeble-mindedness" was thus unconstitutional. The Court rejected that argument in *Buck v. Bell, Superintendant of the Virginia Colony for Epileptics and Feeble Minded*, 274 U.S. 200, 207 (1927), the apotheosis of this century's eugenic hysteria.[2]

Leaving handicapped children to die,[3] like compulsory ster-

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2. *Buck* expressed the era, ratified the view of the feebleminded as "a menace" by juxtaposing the country's "best citizens" (nonhandicapped persons) with those who "sap the strength of the state" (handicapped people), and, to avoid "being swamped with incompetence," held: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." 274 U.S. at 207.

The argument in *Buck* was not new. *See, e.g.*, Brief for the State of Kentucky, *Berea College v. Kentucky*, 211 U.S. 45 (1908) ("the progress, advancement, and civilization of the twentieth century . . . must be left not only to the unadulterated blood of the Anglo-Saxon-Caucasian race, but to the highest types and geniuses of that race. . . ."), *quoted in* R. KLUGER, SIMPLE JUSTICE 87 (1975).

3. This case concerns the denial of standard medical attention to redress an acute, lifethreatening medical condition for a child who also has, and will continue to have, a lifelong disability, *medical care which, if given, will allow the child to live*. This case raises *no* question concerning medical care that would only prolong dying. Characteristically, the matter here concerns retarded or physically handicapped children who require feasible, lifesaving surgery to correct a common, usually unrelated health problem (*e.g.*, an esophagus or stomach blockage, or a heart lesion, or an open spinal column)

ilization, exclusion from communities, and lifelong segregation of disabled people into destructive institutions[4] are part of the history of purposeful unequal treatment addressed by five Justices last Term in *Cleburne*, "the history," Justice Stevens with the Chief Justice wrote, "of unfair and often grotesque mistreatment" imposed "through prejudice and ignorance."[5] 105 S.Ct. at 3262. Describing the sources of the "regime of state-mandated segregation and degradation," Justice Marshall with Justices Brennan and Blackmun wrote:

> "Fueled by the rising tide of Social Darwinism, the 'science' of eugenics, and the extreme xenophobia of those years, *leading medical authorities* and others began to portray the 'feebleminded' as a menace to society and civilization . . . responsible in large degree for many if not all of our social problems." *Id.* at 3266 (emphasis added).[6]

An apparent majority of the *Cleburne* Court declined to address the historical legacy or to exact a heightened scrutiny of

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NOTES *(Continued)*

which will result in their death unless corrected.

The medical and bioethical literature draws a sharp distinction between postponing death, by maintaining the life of the body where the underlying, lifethreatening condition cannot be corrected, and lifesaving corrective surgery for a child who is and will be handicapped. *See, e.g.*, V. BARRY, MORAL ASPECTS OF HEALTH CARE 409 (1982); C. E. KOOP, THE RIGHT TO LIVE, THE RIGHT TO DIE 89-90 (1980); J. BEHNKE & S. BOK, THE DILEMMAS OF EUTHANASIA 103 (1975); *see also* Shaw, *et al.*, *Ethical Issues in Pediatric Surgery*, 60 PEDIATRICS 588, 590 (1977).

4. Contemporary institutional conditions have been found by the Court to be dangerous to those confined therein, *see Youngberg v. Romeo*, 457 U.S. 307, 315-16 (1982); *Pennhurst St. School & Hosp. v. Halderman*, 451 U.S. 1, 7 (1981), as they have been also in the cases of every public retardation institution to be scrutinized by a district court, *e.g.*, *Association for Retarded Citizens of N. Dak. v. Olson*, 561 F.Supp. 473, 484-88 (D.N.Dak.1982) (collecting some of the cases), *aff'd*, 713 F.2d 1391 (8th Cir. 1983).

5. The history of this era's state-approved denial of medical assistance to handicapped children who, with medical attention to correct an acute health condition, would not die is set forth *infra*, pp. 9-14.

6. The continuing prevalence and virulence of these views among medical professionals is set forth *infra*, pp. 15-18.

classifications disadvantageous to retarded people[7] on the ground that "the distinctive legislative response [of 1972-75] . . . belies a continuing antipathy or prejudice." *Id.* at 3256.[8]

This case concerns one of the related laws cited by the *Cleburne* majority as the "distinctive legislative response." Section 504 and each of the contemporaneously adopted statutes were enacted avowedly to reverse the history of prejudice, to admit disabled people fully to the benefits of equal citizenship. Amici submit, however, that the recent course of the Court's decisions on the very federal disability statutes invoked in *Cleburne* go a substantial distance toward nullifying the "legislative response."[9] This is the first case since *Cleburne* to deter-

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7. *But see* Justice Stevens' and the Chief Justice's distinct and apparently different views, 105 S.Ct. at 3261 & n.6. *And see* the views of Justices Marshall, Brennan and Blackmun, *id.* at 3265-68.

8. And belies, the Court majority wrote, "a corresponding need for more intrusive oversight by the judiciary." *Id.* Since *Cleburne* was a constitutional case the Court could not have meant to negate judicial oversight in the enforcement of a federal statute.

9. Section 504 — which, *Cleburne* says, "outlawed discrimination against the mentally retarded in federally funded programs," 102 S.Ct. at 3256 — was held three days earlier not to be privately enforcible by a federal court against a state agency, *Atascadero St. Hosp. v. Scanlon*, 105 S.Ct. 3142 (1985), and in *Southeastern Community Coll. v. Davis*, 442 U.S. 397, 405 (1979), was construed not to require "substantial modifications in [State] programs to allow disabled persons to participate."

The Developmentally Disabled Assistance and Bill of Rights Act of 1975, Section 111, 42 U.S.C. §6010 — in which, *Cleburne* says, "the federal government . . . has also provided the retarded with the right to receive appropriate treatment, services and habitation in a setting that is least restrictive of [their] personal liberty," 102 S.Ct. at 3256 — was held in *Pennhurst I*, 451 U.S. 1, 16 n.12 (1981), to create "no rights whatsoever."

The Education of the Handicapped Act, 42 U.S.C. §§1400-15 — which, *Cleburne* says, requires an " 'appropriate' education" for all handicapped children, 105 S.Ct. at 3257 — was held in *Board of Education v. Rowley*, 458 U.S. 176, 200 (1982), to require merely an education 'sufficient' to confer *some* educational benefit upon the handicapped child" (emphasis added), despite Congress' requirement that education authorities systematically use demonstratedly effective educational programs, 20 U.S.C. §§1400(b)(7), 1413(a)(3).

mine whether one of these statutes shall be given its plain meaning, whether the undertaking of the other two Branches to reverse the regime and admit severely disabled persons to the benefits of our society shall be given judicial respect.

Here the issue is whether Section 504, a plenary civil rights statute[10] which facially and categorically prohibits any "exclu[sion]" of handicapped persons by reason of a handicap "from the participation in any program or activity receiving federal financial assistance" as well as "deni[al] of the benefits of . . ." any assisted program or activity, and any "discrimination" in such programs, does so.[11]

NOTES *(Continued)*

Section 503 of the Rehabilitation Act of 1973, 29 U.S.C. §793, nearly uniquely among statutes explicitly requires "affirmative action to employ and advance in employment qualified handicapped individuals" by "part[ies] contracting with the United States" — thus by its terms conferring duties upon employers, and opportunities for productive work on severely disabled people, which significantly exceed the employment rights established by the Civil Service Regulation recited in *Cleburne*, 105 S.Ct. at 3256 — has been held by nine Courts of Appeal *not* to be enforceable in a private right of action with *certiorari* six times denied here, *e.g.*, *Hodges v. Atchinson Rwy. Co.*, 728 F.2d 414 (10th Cir.), *cert. denied*, 105 S.Ct. 97 (1984); *but see Drennon v. Phila. Gen. Hosp.*, 428 F.Supp. 809 (E.D. Pa. 1977) (Higginbotham, *J.*); *Rogers v. Frito Lay, Inc.*, 611 F.2d 1074, 1085 (5th Cir.) (Goldberg, *J.*, dissenting), *cert. denied*, 449 U.S. 889 (1980); *Davis v. United Airlines, Inc.*, 662 F.2d 120, 127 (2d Cir. 1981) (Kaufman, *C.J.*, dissenting), *cert. denied*, 456 U.S. 965 (1982).

10. *New York St. Ass'n for Retarded Children v. Carey*, 612 F.2d 644, 649 (2d Cir. 1979). *See also NAACP v. Wilmington Med. Ctr.*, 599 F.2d 1247, 1258 & n.47 (3d Cir. 1979); *Lloyd v. Regional Transp. Auth.*, 548 F.2d. 1277, 1280-84 (7th Cir. 1977).

11. The practice in issue here violates each clause of Section 504, but, amici submit, is most directly addressed as "an exclusion from" and "a denial of the benefits of" assisted programs and activities. The "program or activity" here is the federally funded hospital. To the extent any programs so assisted (and the vast majority are) may exclude or deny its benefits to handicapped children, *Grove City Coll. v. Bell*, 104 S.Ct. 1211, 1220 (1984), presents no concern.

I. HISTORICALLY AND NOW, ACTING FROM IGNORANCE AND PREJUDICE ESTABLISHED IN AN EARLIER ERA, PROVIDERS OF HEALTH SERVICES HAVE DENIED PERSONS WITH LIFELONG DISABILITIES THE BENEFITS OF THEIR SERVICES AND HAVE, WITH SINGULARITY ON THE BASIS OF A HANDICAP, WITHHELD LIFESAVING MEDICAL SERVICES.

Section 504 and the contemporaneous statutes of which it is the keystone represent a conscious decision by Congress to reverse "the regime of segregation and degradation" imposed on disabled people in the early decades of the century, to eliminate the legacy of "ignorance and prejudice" acknowledged in *Cleburne*. The practice at issue here is of the regime and continues for reasons of ignorance and prejudice rooted in the regime.

The *New York Times*, November 18, 1915, in a Page One report, "Defective Babe Dies as Decreed: Physician, Refusing Saving Operation, Defends Course as Wisest for Country's Good," gives an historical example of the awful practice:

> "John Bollinger, the boy baby condemned as a hopeless defective and therefore not operated on, died early this evening in the German-American Hospital. The child was five days old. . . .
>
> "Its life, Dr. H. J. Haiselden, the attending physician, said, might have been saved by an operation, but this he did not feel justified in performing. The partial paralysis and the malformations, he said, were so great a bar to happiness or attainment that he did not feel justified in saving the baby from the death which nature ordained. . . .
>
> "Coroner Hoffman said tonight: 'I do not believe there will be an inquest. The case is not different from many others. . . .'

"State's Attorney Hayes said privately that he approved the physician's refusal to act in the case. Officially, since there appeared a basis for legal action, he would express no opinion. . . .

"Dr. Haiselden in discussing his action said tonight: 'I rest with my conscience. There was no chance that life would bring this child anything better than an animal existence and imbecility. . . . I believe I have done the child, its parents, who agree with me, and the race a favor in taking the course I did. . . .'

"Many persons had asked permission to take the baby to their homes and have it cared for by other surgeons. Women pleaded, and at least one vented her wrath in epithets of the bitterest nature."[12]

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12. The baby died of an imperforate anus that could have been treated with simple surgery. Dr. Haiselden, the hospital's Chief of Staff and a staunch eugenicist who in his practice sterilized "defective" children, announced to the press that he would allow the child, who otherwise would be a "burden to society," to die of autointoxication. S. L. Kuepper, Euthanasia in America, 1890-1960, at 70 (Rutgers Univ. diss. 1981), *citing* Columbus (Ohio) Evening Dispatch, Nov. 17, 1915, at 2; Chicago Daily News, Nov. 19, 1915, at 3; Chicago Tribune, Nov. 17, 1915 at 1. Dr. Haiselden suggested that the child, like other "defectives," would be prone to criminality, and called on other physicians to follow his example, to tend only the fit, "so that by the weeding out of our undesirables we decrease their burden and ours and lay the foundation for a normal human race." Philadelphia Inquirer, Nov. 19, 1915, at 7. Even when ordered by the Health Commissioner to operate, Dr. Haiselden steadfastly refused, stating that he did "not believe it would do justice to the human race." Kuepper, *supra* at 71. Most physicians who spoke out on the issue agreed with Dr. Haiselden, and The Medico-Legal Society adopted a resolution supporting him. *Id*. at 73. Dr. W. C. Woodward, the District Health Officer, observed that the very existence of the controversy showed that "the public conscience with respect to such cases is changing. . . . A few years ago, the condemnation of mother and physician would have been universal." *Id*., *citing* Chicago Tribune, Nov. 18, 1915, at 2 . The *Medical Standard*, a physicians' journal, sponsored a roundtable at which seven of ten participants agreed that death was an acceptable alternative for severely handicapped babies. *The Defective Child*, 89 MEDICAL STANDARD 35-42 (1916). The mother of another "Haiselden baby," a child with microcephaly, later deeply regretted that her child had been allowed to die and urged parents of handicapped infants in need of lifesaving

This report is not an isolated example but is part of the "regime." "By the latter part of the century and during the first decades of the new one," Justice Marshall noted in *Cleburne*, beliefs concerning handicapped people "underwent a radical transformation," 105 S.Ct. at 3266, and social preoccupation with eugenics "reintroduced an attitude favoring the killing of defective children."[13] Some physicians, in fact, advocated that the unfit be actively eliminated. In 1906, a distinguished Chicago physician endorsed the "destruction" of handicapped persons on eugenic grounds: "In strict justice to society . . . and in many cases in all kindness to the defective himself, every degenerate who is useless to himself, a menace to the health of society, and is shown to be incurable should be effectively eliminated by destruction."[14] A respected New York physician, W. Duncan McKim, advocated the elimination of all severely handicapped children, including "idiots," most "imbeciles," and the greater number of epileptics, for society's protection, via a "gentle, painless death" by the inhalation of carbonic gas.[15]

Although the eugenic hysteria of the era abated, physicians continued to support the view that the "defective" and the "feeble-minded" should die. In the wake of a physician's admission that he had put to death a child "clearly doomed to imbecility," the *Journal of the American Medical Association* observed that doctors frequently face this situation and generally decide it their way without interference. A Nobel Prize winner at the Rockefeller Institute similarly urged that "sentimental prejudice . . . not obstruct the quiet and painless disposition of incurables, criminals, and hopeless lunatics."[16]

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medical treatment to save their lives. Chicago Tribune, May 8, 1938, §1, at 2.

13. D. B. Shurtleff, *Myelodysplasia: Management and Treatment*, 10 CURR. PROBS. IN PEDIATRICS 1, 8 (1980).

14. G. FRANK LYDSTON, M.D., DISEASES OF SOCIETY 568 (1906).

15. D. MCKIM, HEREDITY AND HUMAN PROGRESS 189, 193 (1900).

16. *The Right to Kill*, TIME, Nov. 18, 1935, at 53-54. *See also* Kennedy, *The Problem of Social Control of the Congenital Defective*, 99 AM. J. PSYCH. 13-16 (1942) (advocating involuntary euthanasia of 60,000 retarded persons in institutions and five times as many outside, since in these "hopeless" cases "we have no fear of error").

This stark history is of course of the regime of segregation and degradation[17] which by force of state statute deemed retarded people to be "unfit for citizenship."[18] In every state in inexorable fashion handicapped persons were legislatively declared a "menace to the happiness . . . of the community,"[19] "unfitted for companionship with other children,"[20] a "blight on mankind"[21] whose very "presence"[22] in the community was "detrimental to normal" people.[23]

Official policy was to "purge society"[24] of these "anti-social beings,"[25] to "segregate [them] from the world,"[26] so that they "not . . . be returned to society"[27] since a "defect . . . wounds our citizenry a thousand times more than any plague."[28] Disabled persons simply did not have the "rights and liberties of normal people."[29] The District of Columbia Board of Charity

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17. The general history of the regime was detailed in APPENDIX A, COMPENDIUM OF PURPOSEFUL STATE ACTION FOR THE SEGREGATION AND EXCLUSION OF RETARDED PERSONS IN THE FIFTY STATES AND THE DISTRICT OF COLUMBIA, BRIEF AMICI CURIAE OF ARC/US, *et al.*, *City of Cleburne, Tex. v. Cleburne Living Ctr.*, 105 S.Ct. 3249 (1985).

Appendix A to this Brief is a COMPENDIUM OF THE MEDICAL LITERATURE OF THE ERA, DESCRIBING PHYSICIANS' PARTICIPATION IN THE GENERAL REGIME AND THEIR RATIONALE FOR ELIMINATING HANDICAPPED CHILDREN.

18. 1920 Miss. Laws 294, ch. 210, §17 *quoted in Cleburne*, 105 S.Ct. at 3267 (Marshall, *J.*, concurring).

19. 1919 Ala. Acts 739, No. 568, §7.

20. 1909 Wash. Laws 260, tit. I., subch. 6, §2.

21. REPORT OF THE VT. SCHOOL FOR THE FEEBLE-MINDED 17-18 (1916).

22. REPORT OF THE R.I. SCHOOL FOR THE FEEBLE-MINDED 21 (1910).

23. CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, FIRST BIENNIAL REPORT 41 (1905).

24. WISCONSIN BOARD OF CONTROL, BIENNIAL REPORT 321 (1898).

25. REPORT OF THE COMMISSION ON SEGREGATION, CARE AND TREATMENT OF FEEBLE-MINDED AND EPILEPTIC PERSONS IN PENNA. 43 (1913).

26. THIRTY-SIXTH ANNUAL REPORT OF THE INDIANA SCHOOL FOR FEEBLE-MINDED YOUTH 14 (1914).

27. FIRST BIENNIAL REPORT OF THE BOARD OF COMMISSIONERS OF NEBRASKA INSTITUTIONS 10 (1915).

28. FOURTH BIENNIAL REPORT OF THE BOARD OF TRUSTEES OF THE UTAH STATE TRAINING SCHOOL 3 (1938).

29. FOURTH BIENNIAL REPORT OF THE SOUTH DAKOTA COMMISSION FOR SEGREGATION AND CONTROL OF THE FEEBLE-MINDED 3 (1932).

urged Congress, and it agreed, to authorize putting handicapped people away since they were "not much above the animal."[30] Handicapped people were "not far removed from the brute,"[31] not quite persons, but "by-products of unfinished humanity"[32] who were to be segregated for the benefit "of society,"[33] "to relieve society of 'the heavy economic and moral losses arising from the existence at large of these unfortunate persons.' "[34] It was important to find a "way of getting rid of these kinds of cases."[35] Government reports labeled handicapped people "a parasitic, predatory class,"[36] a "danger to the race,"[37] "a blight and a misfortune both to themselves and to the public"[38] whose role "in discounting social progress is by far the most potent influence for evil under which society is struggling today."[39]

State officials actively inculcated fear of handicapped persons, especially retarded persons, directed their identification and removal from the community, and coerced the assistance of physicians, health workers, and a variety of others to do so, *even* against parental instincts to harbor them.[40] State statutes di-

30. *District of Columbia Appropriations Bills, Hearings Before the Comm. on Appropriations*, 67th Cong., 2d Sess. 96 (Jan. 13, 15, 1923).

31. MENTAL DEFECTIVES IN VIRGINIA: SPECIAL REPORT OF THE BOARD OF CHARITIES AND CORRECTIONS TO THE GENERAL ASSEMBLY OF 1916, at 20.

32. Baldwin, *The Causes, Prevention and Care of Feeble-Minded Children*, in PROCEEDINGS OF THE TEXAS CONFERENCE OF CHARITIES AND CORRECTIONS AT ITS SECOND ANNUAL MEETING 87 (1912).

33. *E.g.*, 1919 Ga. Laws 379, No. 373, §3.

34. *Cleburne*, 105 S.Ct. at 3267 n.9 (Marshall, *J.*, concurring), *quoting* 1915 Tex. Gen. Laws 143, ch. 90, §§1, 2.

35. *Connecticut School for Imbeciles: Hearings on H. B. No. 644 Before the Joint Standing Committee on Humane Institutions* 20 (typed transcript, Feb. 25, 1915) (statement of Mr. Kerner of Waterbury).

36. REPORT OF THE VERMONT SCHOOL FOR FEEBLE-MINDED CHILDREN 17-18 (1916).

37. *Report of the Legislative Visiting Committee*, WISC. SEN. J. 263 (48th Leg. Sess.).

38. THIRTEENTH BIENNIAL REPORT OF THE KANSAS SCHOOL FOR FEEBLE-MINDED YOUTH 12 (1906).

39. MENTAL DEFECTIVES IN INDIANA: THIRD REPORT OF THE COMMITTEE ON MENTAL DEFECTIVES 6 (1922).

40. *E.g.*, 1915 N.C. Sess. Laws 337-38, ch. 266, §3; 1931 S.D. Sess. Laws 200, ch. 153, §§3(b), (c); 1918 Ky. Acts 171, ch. 54, §30; 1917 Or. Laws 739,

rected others to put away the child if the parent or relative "should neglect or refuse" to do so.[41] One statute made it a criminal offense punished by a $200 fine for a *parent* to refuse.[42] Statutes required parents to "waive all right to remove such inmate thereafter either permanently or for a limited time,"[43] to keep from society disabled children "whose parents or guardians are averse to such actions."[44] States officially made the judgment that "the presence of the unfortunate child in the home"[45] was "more tragic than any known disease,"[46] and a "menace to . . . the family."[47]

The views and practices of physicians in issue here and the vulnerability of new parents of handicapped children[48] are the

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NOTES *(Continued)*

740, ch. 354, §§5; CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, EIGHTH BIENNIAL REPORT 51 (1918); 21ST BIENNIAL REPORT OF THE KANSAS TRAINING SCHOOL 3 (1922).

41. 1920 Miss. Laws 294, ch. 210, §17; 1921 W. Va. Acts 480, ch. 131, §4(a); *see* 1919 Ala. Acts 740, No. 568, §9 ("notwithstanding the family or relatives may object thereto"); 1909 Okla. Sess. Laws 538, ch. 34, art. 2, §8.

42. 1905 Wash. Laws 135, ch. 70, §9.

43. 1905 Mich. Pub. Acts 169-70, No. 121; 1919 N.J. Laws 508, ch. 217, §3; *accord*, 1919 Mont. Laws 198, ch. 102, §9; 1909 N.D. Sess. Laws 317-18, ch. 213, §1.

44. CALIFORNIA BOARD OF CHARITIES AND CORRECTIONS, BIENNIAL REPORT 30 (1916); *accord*, FIRST BIENNIAL REPORT OF THE BOARD OF COMMISSIONERS OF NEBRASKA INSTITUTIONS 11 (1915) (need for disabled children to be "detained in the institution against the desire of the parent").

45. REPORT OF THE R.I. SCHOOL FOR THE FEEBLE-MINDED 21 (1910).

46. FOURTH BIENNIAL REPORT OF THE UTAH TRAINING SCHOOL 3 (1938).

47. 1885 Cal. Stats. 198, ch. 156, §8; 1906 Md. Laws 653, ch. 362. These authoritative state instructions were the counterpoint to President Kennedy's Special Message, February 5, 1963, requesting Congress "to reinforce the will and capacity of our communities to meet these problems in order that the communities, in turn, can reinforce the will and capacity of individuals and individual families." 109 Cong. Rec. 1842. The disability rights laws of 1972-1975 were a response to this call and were enacted to reverse the instructions of the earlier era. *See* Argument II *infra*, pp. 19-28.

48. Who after all, before they in one swift moment have become parents of children with a lifelong handicap, are just people schooled in the ordinary ignorance and prejudice an entire era was dedicated to establishing.

fruits of this period. The singular exception for persons with lifelong disabilities in the otherwise constant and professionally fundamental commitment of medical professionals to sustain life[49] is expressed still in precisely the terms popularized and established in that "most xenophobic era," *Cleburne*, 105 S.Ct. at 3266.

During the current decade there has been an explosion of articles in medical journals reporting in detail the practice of withholding lifesaving medical assistance from children who have lifelong handicaps, and setting forth justifications for doing so.[50] The studies reveal that many physicians, a majority in some specializations, oppose lifesaving surgery for babies with lifelong disabilities.[51] These publications, in language and substance exactly akin to the "science" of the earlier era, *Cleburne*, 105 S.Ct. at 3266, assert three rationales: (1) on a cost-benefit basis, society

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49. For the historical commitment of the medical profession to life and the singularity of this exception, *see* O. Temkin, *et al.*, RESPECT FOR LIFE IN MEDICINE, PHILOSOPHY AND THE LAW (1977); D. CRANE, THE SANCTITY OF SOCIAL LIFE (1975); J. DUFFY, THE HEALERS (1976); E. FREIDSON, PROFESSION OF MEDICINE (1975); I. ABT & F. GARRISON, HISTORY OF PEDIATRICS (1965).

50. Gross, *et al.*, *Early Management and Decision-Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983); Affleck, *Physicians' Attitudes Toward Discretionary Treatment of Down's Syndrome Infants*, 18 MENTAL RETARDATION 79 (1980); Todres, *et al.*, *Pediatrician's Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977); Shaw, *et al.*, *supra* note 3; Darling, *Parents, Physicians and Spina Bifida*, 7 HASTINGS CTR. REP. 10 (1977); Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 N.ENG.J. MED. 890 (1973). *And see* D. CRANE, *supra* note 49; *cf.* J. Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BRIT. MED. J. 201 (1973).

51. In a survey of members of the Surgical Section of the American Academy of Pediatrics, for example, 76.8% of pediatric surgeons and 49.5% of pediatricians reported they would not insist upon surgery in a newborn with intestinal atresia if the infant also had Down Syndrome, while only 7.9% and 2.6% respectively would not if the child was nonhandicapped. The physicians surveyed ranked the infant's "potential quality of life," probable IQ, and adverse effects on the family high among criteria for deciding whether to withhold surgery. Shaw, *et al.*, *supra* note 3, at 590. Massachusetts pediatricians confessed similar beliefs for a baby with Down Syndrome and an even more striking preference for nontreatment of a baby wtih severe spina bifida (67% said they would recommend to the parents that surgery not be performed). Todres, *et al.*, *supra* note 50, at 197-99.

would be better off without the child;[52] (2) the burdens the child would impose on the family are greater than any benefits to be derived;[53] (3) the intrinsic value of the child's life is very little.[54] Each asserted rationale is counterfactual, is based on ignorance and prejudice, and is contrary to congressional findings.[55] Physicians' categorical assumption that severely handicapped children are a familial or societal burden are, in amici's considerable experience, plainly wrong.[56] Competitive employment and supported work programs have demonstrated without doubt the capacity of severely handicapped adults for productive employment.[57] Just as others, severely disabled persons experience

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52. *E.g.*, "no child with Down's Syndrome ever grew up to be self-sustaining," Crile, *The Right to Life*, Medical Tribune, December 19, 1984; severely handicapped persons have "no prospect . . . of employment," Lorber, *supra* note 50, at 202; Down Syndrome persons are not "capable of being useful," Shaw, *et al.*, *supra* note 3, at 595; their "potential usefulness" is nil, D. CRANE, *supra*, note 49, at 55.

53. *E.g.*, "As far as having a mongoloid child, I can't come up with anything satisfying about it, I can't think of anything good it does." Darling, *supra*, note 50, at 11. Down syndrome children bring "frustration and sadness," "rarely" love and happiness into the home. Shaw, *et al.*, *supra* note 3, at 595.

54. Severely handicapped persons have "little or no hope of achieving meaningful 'humanhood' " and "little or no capacity to love or be loved," Duff & Campbell, *supra* note 50, at 892; and a poor "quality of life," Gross, *et al.*, *supra* note 50, at 450, 456; physicians define severely handicapped persons' lives as "intolerable." Darling, *supra*, note 50, at 13.

55. Argument II, *infra*, sets forth the congressional findings.

56. Darling, *supra* note 50, at 11 (survey reports parents love their disabled children and view their own parenting situation positively); Burt, *Constitutional Law and the Teaching of the Parables*, 93 YALE L. J. 455, 495 (parents of handicapped persons hope for their children's full inclusion in the community); *See Wyatt v. Aderholt*, 503 F.2d 1305, 1312 & n.8 (5th Cir. 1974) (segregation of handicapped persons for their families' convenience morally and constitutionally impermissible); Wald, *State Intervention on Behalf of 'Neglected' Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975) (parents' failure to provide lifesaving medical treatment constitutes abuse at common law); Joint Commission on Juvenile Justice Standards, Standards Relating to Abuse and Neglect Recommended by the IJA/ABA (1981) (failure to provide lifesaving medical treatment constitutes abuse and neglect).

57. WEHMAN, COMPETITIVE EMPLOYMENT: NEW HORIZONS FOR THE SEVERELY DISABLED (1981); G. T. BELLAMY, VOCATIONAL HABILITATION OF SEVERELY RETARDED ADULTS: A DIRECT SERVICE TECHNOLOGY (1979).

joy and contribute to society.[58]

The familiar rationale for eliminating children with severe handicaps arises still from the familiar ignorance. In 1962, the President's Panel on Mental Retardation found unacceptably high the frequency of "decisions [by medical professionals] based on erroneous expectations as to the child's capacity" and concluded "physicians need special orientation to the nature and implications of physical and intellectual disabilities."[59]

The American Academy of Pediatrics reports[60] that 50.5% of pediatricians identify as "insufficient" their learning about ". . . handicapped children" and The Academy itself identified "handicapping and chronic conditions" foremost among "subjects in which education content is inadequate" and among "the underemphasized areas in pediatric residencies."[61]

In Nebraska, for example, where a system of community services for retarded people had long since been well established, most pediatricians (81%) and general practitioners (79%) still regularly recommended institutionalization even for

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58. J. P. EDWARDS, WE ARE PEOPLE FIRST: OUR HANDICAPS ARE SECONDARY (1982); P. WILLIAMS & B. SHOULTZ, WE CAN SPEAK FOR OURSELVES (1982).

59. PRESIDENT'S PANEL ON MENTAL RETARDATION, REPORT TO THE PRESIDENT: A PROPOSED PROGRAM FOR NATIONAL ACTION (1962). Two decades later, still, a survey comparison of pediatricians with nonmedical professionals found:

> "[P]ediatric practitioners respond less optimistically than educators or psychologists toward the mentally retarded child. Often they may begin their examination with an already established poor prognosis of the child's future functioning, resulting in serious implications for the type of placement options presented to the family home, institution, special school." Wolraich & Siperstein, *Assessing Professionals' Prognostic Impression of Mental Retardation*, 21 MENTAL RETARDATION 8, 10 (1983). "Pediatric training," the authors observe "typically involves minimal exposure to mental retardation." *Id.* at 10.

60. THE FUTURE OF PEDIATRIC EDUCATION: A REPORT BY THE TASK FORCE ON PEDIATRIC EDUCATION (1977).

61. Significantly, modern services to severely disabled people depend upon educators, occupational and physical therapists, vocational specialists and psychologists, not physicians. *See* Amici Brief of AAMD, TASH *et al.*

"moderately" retarded children.[62] Given the deficits of knowledge among physicians it is not surprising they should be supplied instead by familiar historically sponsored and established prejudice and stereotypes.

The President of the American Academy of Pediatrics has suggested that too much has been made of surveys, that pediatricians are better informed about handicaps than they were even in the 1970s;[63] however, there is ample evidence that the practice of refusing life-saving medical treatment may be even more common than survey studies would predict.[64]

In any event, Congress has flatly rejected the practice by its enactment of Section 504 and the other disability laws of the early 1970s. It is to those laws, the Congressional findings upon which they are based, and the Congress' purposes in enacting them, that amici now turn.

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62. Kelly & Menolascino, *Physicians' Awareness and Attitudes Toward the Retarded*, 13 MENTAL RETARDATION, Dec., 1975, at 10 (1975) (40% of parents advised to institutionalize their child (86% within a year of diagnosis), but "not one of these children is presently residing in an institution").

63. Strain, *The Decision to Forego Life Sustaining Treatment for Seriously Ill Newborns*, 72 PEDIATRICS 572 (1983).

64. A report on the results of selection of handicapped newborns for treatment between 1977 and 1982 at Oklahoma University Health Sciences Center showed that babies were provided — or denied — treatment based on such factors as their estimated intelligence and ambulatory potential, according to a "formula" that also factored in the "contribution anticipated from his home and family and society." Gross, *et al.*, *supra* note 50, at 456. A study has documented that surgeons at a teaching hospital were actually *less* likely to perform surgery on Down syndrome children with heart defects than survey studies would predict. D. CRANE, *supra* note 49, at 96-98.

II. BY ITS PLAIN MEANING, ITS STRUCTURE, AND THE EXPRESS INTENTION OF THE CONGRESS SECTION 504 WAS ENACTED TO REVERSE THE REGIME OF SEGREGATION AND DEGRADATION EARLIER IMPOSED UPON HANDICAPPED PERSONS AND TO BAR THE WITHHOLDING OF LIFE-SAVING MEDICAL ASSISTANCE.

The plain language of Section 504 prohibiting any "exclus[ion] from" or "denial of the benefits of any federally assisted program or activity" on the ground of handicap, and its "legislative heritage" as a civil rights statute in which the other two Branches conclusively adopted the analogy of handicap to race[65] are sufficient to command a reversal here. Amici do not rehearse that argument, as it is set forth compellingly in Judge Winter's dissenting opinion in *University Hospital*, 729 F.2d at 161-62, and addressed in the briefs of others here. Rather, amici direct the Court's attention to the legislative history of Section 504 and the several related, contemporaneous enactments, for there is nothing in this case that Congress did not comprehend in the course of formulating those statutes.

The significance — historic and legal — of Congress' decision to establish handicap as a basis for civil rights protection cannot be overstated. The legislative history of Section 504 and each of the directive statutes enacted during four legislative years, 1972-1975,[66] show that Congress understood the history of

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65. Section 504 was patterned after Title VI and Title IX and was originally introduced as an amendment to Title VI. When that amendment was inserted into vocational-rehabilitation legislation then pending, its language, principle and intent was carried forward into §504, as the Court recognized unanimously in *Alexander v. Choate*, 105 S.Ct. 712, 718 & n.13 (1985).

66. The Court has frequently directed that legislative history of related enactments be read to inform each of them. *E.g.*, *Albemarle Paper Co. v. Moody*, 422 U.S. 405, 416 (1975). Section 504 was proposed, considered and enacted contemporaneously with the Education of the Handicapped Acts ("EHA") of 1974 and 1975, 20 U.S.C. §§1400-1415; the Developmentally Disabled Assistance and Bill of Rights Act of 1975, 42 U.S.C. §§6000, *et seq.*; the Rehabilitation Act of 1973 proper and the succeeding Rehabilitation Amendments of 1974, 29 U.S.C. §§701, *et seq.*; and the remaining provisions of Title V, the civil rights title, of the Rehabilitation Act, 29 U.S.C §§791-795. The

disability discrimination, was moved by the continuing destructive effect of the regime of state-mandated segregation and degradation, including its perpetuation in the matter here, and acted to reverse that regime, root and branch, and to eliminate its legacy. In short, Congress said, of course a severe, lifelong disability is handicapping, but more handicapping have been the "extreme xenophobic," "grotesque" reactions of society to persons with disabilities. This congressional history is the primary guide to construing Section 504.

On the basis of the extensive and pointed legislative record the decision below should be reversed and Section 504 and its related enactments given their intended meaning and effect.[67] Otherwise "handicapped persons will be deprived of a fairly won political victory and exposed to the possibility of future decisions excluding other services from Section 504 . . ." *University Hospital*, 729 F.2d at 162-63 (Winter, *J*., dissenting).[68] "It is not enough to say to the Congress, we see what you are driving at . . . but we shall go on as before." *Johnson v. United States*, 163 F. 30,32 (lst Cir. 1908) (Holmes, *J*., on circuit).

NOTES *(Continued)*

EHA and the Bill of Rights Act were initially proposed in 1972 and the subjects of hearings, reports and floor action in 1973, 1974 and 1975. The Rehabilitation Act proper was initially proposed in 1972 and was the subject of hearings, reports and floor consideration in 1972, 1973 and 1974. The hearings and reports from this extensive legislative record are compiled in Appendix B.

67. It would, for example, benefit handicapped persons insufficiently and betray the congressional undertaking were it to be held that Acts of Congress require lifesaving medical assistance after birth but do not prohibit institutional segregation. As Joseph Goldstein has written:

> As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than either assume full responsibility for the treatment, care, and nurture of such children or honor the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life. *Medical Care for the Child at Risk* in W. GAYLIN & R. MACKLIN, WHO SPEAKS FOR THE CHILD 153 (1982).

68. *See also Cleburne*, 105 S.Ct. at 3257.

In Section 504, and the related enactments, Congress had in mind not only the mildly or moderately disabled, the cosmetically handicapped, those who found it relatively easy to "make it"; rather Congress acted knowingly and expressly especially on behalf of those with *severe*, usually *lifelong disabilities* (and acted to supply the conditions under which they can make it). Congressman Vanik, Senator Humphrey, and Senator Percy, introducing what became Section 504, each focused upon "the most severely handicapped." 117 CONG. REC. 45974 (1971); 118 CONG. REC. 526 (1972).[69] Handicapped persons who had been "shunted aside, hidden, ignored," "behind closed doors,"[70] 117 CONG. REC. at 45974, "the 'expendables'," as Senator Humphrey described them, 118 CONG. REC. at 9495, were the primary intended beneficiaries of Section 504.[71]

The central purpose of Section 504, as numerous statements made in the course of its formulation show, was to disestablish the regime of "segregation and degradation." As Senator Humphrey squarely put it: "The fundamental fact one confronts

69. A unanimous Court in *Alexander*, 105 S.Ct. at 718 nn.13 & 15, said the views of Congressman Vanik and Senators Humphrey and Percy are to be given particular weight in interpreting the legislative history of Section 504. Ultimately, Section 504 was cosponsored by 60 House members and 20 Senators. 118 Cong. Rec. 9495 (1972), and the Rehabilitation Act of 1973 including Section 504 was passed unanimously. 1973 CONG. Q. ALM. 557, *et seq*.

70. Resolving that the Congress would "no longer tolerate the invisibility of the handicapped in America," 117 Cong. Rec. at 45974 (statement of Rep. Vanik), the progenitors of Section 504 understood the sustaining mechanism of ignorance and prejudice, as Justice Marshall wrote in *Cleburne*, the "lengthy and continuing isolation of the retarded has perpetuated the ignorance, irrational fears and stereotyping that have long plagued them," 105 S.Ct. at 3267.

71. In the Rehabilitation Act — "the major vocational-rehabilitation bill then pending" — into which Congress inserted 504 and other civil rights provisions, *Alexander*, 105 S.Ct. at 718 n.13, Congress required that vocational-rehabilitation "serve *first* those with *the most severe* handicaps." 29 U.S.C. §§701(1), 721(a)(5); *see also id*. §§741(a), 750(a), 762, 772(b), 774(b). The EHA was enacted in 1974-75 by Congresses similarly cognizant that the greatest number of handicapped children theretofor excluded from school altogether had severe disabilities, and required that State and local education authorities "establis[h] priorities for providing a free public education to all handicapped children . . . with respect to handicapped children, within each disability, with the *most severe handicaps*." 20 U.S.C. §§1412(3), 1414(a)(6).

is . . . the segregation of [these] Americans from society. . . . This bill [addresses] handicapped children, youth and adults who suffer the profound indignity and despair of isolation, discrimination and maltreatment." Congress understood the historical origins of current conditions in "the deliberate segregation of the handicapped" and in their "resulting invisibility," 118 CONG. REC. at 9497-98 (Sen. Humphrey), in the historical but continuing view that "handicapped children were a physical threat[,] uneducable, . . .[and], nauseating," 117 CONG. REC. at 45974 (Rep. Vanik), in the regime established on the basis of the "danger" and "hopeless incapability" of disabled people, 118 CONG. REC. at 526 (Sen. Percy).

Section 504 was enacted as a sharp break with that history, to repudiate it, to reverse its legacy. "In essence, our amendment will give the handicapped their rightful place in society." 118 CONG. REC. at 526 (Sen. Percy). [Section 504] carries through the intent of the original bills . . . to end the virtual isolation of children and adults from society." *Id.* at 32310 (Sen. Humphrey).[72] To do so, Congress understood, required reor-

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72. Ending the distinctive institution of segregation itself, the keystone creation of the historical regime, was a central purpose and intended effect of Section 504:

> "In this country we still have the snake-pit mental institutions — institutions for confinement not treatment, where brutality and unexplained deaths are common. . . ." 117 CONG. REC. at 45974 (Rep. Vanik).
>
> "I am calling for public attention to three-fourths of the nation's institutionalized retarded people who live in public and private residential facilities which are more than 50 years old, functionally inadequate, and designed simply to isolate those persons from society." 118 CONG. REC. at 525 (Sen. Humphrey).
>
> ". . . retarded and other handicapped people must become as much as possible a part of society, living and working in the community. . . . The vehicle for integrating the retarded into the community is the group home where retarded children — or adolescents or younger or older adults — can live beyond the wards of institutions with the assistance of non-retarded house-parents." *Id.* at 9500-01; *accord, id.* at 526; 117 CONG. REC. at 42293-94 (Sen. Percy).

In the Senate Report accompanying the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. §6010, whose plain terms were in

dering the basic relationship between handicapped people and the so-called "normal" society.[73]

In the course of resolving to eliminate the historical regime, root and branch, Congress came to a knowledge of the capabilities and prospects of severely disabled people entirely different from that which underlay the regime and that continues today still to be boldly offered in justification of withholding lifesaving medical assistance. Congress' systematic finding plainly underlying Section 504 and every one of the related enactments, is that *severely* disabled people, as a matter of fact, can *live* and *learn* and *work productively* in — and as integral members of — the community and that it is impermissible even to suggest that people with severe disabilities are "expendable" or that "their lives are not worth living." For example, as to the facts, Congressman Vanik recognized that "handicapped children, even the most severely handicapped, do learn when given the chance to participate in educational programs tailored to meet their special needs." 118 CONG. REC. at 526. Contemplated throughout the legislative history of Section 504 was the "opportunity for education, job training, productive work," *id.* (Sen. Percy), "a productive and [even] financially independent life" for handicapped persons "no matter how severe his or her degree of disability,"[74]

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harmony with the Court's opinion in *Cleburne (but see Pennhurst I*, 451 U.S. 1 (1982)) — the same Senate Committee that incorporated Section 504 wrote: "It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. [T]he fact [is] that most of these institutions are anachronisms, and that rapid steps should be taken to phase them out." S. Rep. No. 160, 94th Cong., 1st Sess. 32-33 (1975).

73. Congress acted, in short, to codify the right of disabled people to "equal citizenship" and "insist[ed] that the organized society treat each individual as a person, one who is worthy of respect, one who 'belongs . . .' presumptively forbid[ding] the organized society to treat an individual either as a member of an inferior or dependent caste or as a non-participant." Karst, *Supreme Court, 1976 Term — Forward: Equal Citizenship Under the Fourteenth Amendment*, 91 HARV. L. REV. 1, 6 (1977); *see also* Baker, *Outcome Equality or Equality of Respect*, 131 U. PA. L. REV. 933 (1983).

74. *See* note 71 *supra*.

117 CONG. REC. at 42294; 118 CONG. REC. at 526.[75]

While formulating "the distinctive legislative response" of Section 504, its 1974 affirmation, and its related enactments, Congress — in three years of hearings on the EHA, three years on the Rehabilitation Act, and three years on the Developmentally Disabled Assistance and Bill of Rights Act — compiled an unprecedented legislative record on the modern understanding of the capabilities of severely disabled people, on modern techniques of assisting disabled people to realize them and historical and contemporary obstacles to achieving them.[76] Based on these findings and in a full exercise of its powers, including particularly its powers to enforce the Fourteenth Amendment, the Congress enacted Section 504 and each of the related enactments. Neither this nor any judicial forum is the place to quarrel with the findings of Congress, with its purposes or with the plain meaning of its enactments, nor is a hospital neonatal ward the place for any such contest. Lifesaving health services are among the federally assisted services Congress sought to reach by Section 504, legislating to open these and all other federally funded benefits fully to severely handicapped persons.[77]

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75. "Where," Senator Humphrey asked, "is the cost-effectiveness in . . . consigning them to 'terminal' care is an institution?"

76. Upon that record the Congress found, in enacting the EHA: "[D]evelopments in the training of teachers and in diagnostic and instructional procedures and methods have advanced to the point that . . . state and local educational agencies can . . . provide effective special education and related services to meet the needs of handicapped children." 20 U.S.C. §1413.

77. Respondent AHA complains that any such application of Section 504 would constitute impermissible "affirmative action" under *Southeastern Community College v. Davis*, 442 U.S. 397, 411-12 (1979). Opp. Cert. Brief of Respondent AHA, at 26. This argument ignores the important gloss placed on that "severely criticized" *Southeastern* passage by *Alexander v. Choate*, 105 S.Ct. at 721 n. 20. The regulation at issue here requires no "fundamental alteration in the nature of a program," *id. quoting Davis*, 442 U.S. at 410, but merely, as Section 504 specifies, that the benefits of that program be provided handicapped persons in a "meaningful" fashion, *Alexander*, 105 S.Ct. at 721. Indeed, the official analysis of the HHS regulation for Section 504 specifies that the agency intended from the beginning "to give particular attention in its enforcement of Section 504 to eliminating discrimination against persons with the severe handicaps that were the focus of concern in the Rehabilitation Act

Rising on the floor of the House on December 9, 1971 to introduce Section 504, Congressman Vanik stated: "Mr. Speaker, the treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights" and immediately singled out the "100,000 *babies* [who] are born *with defects*" annually among the "masses of the handicapped [who] live and struggle among us, often *shunted aside*, hidden and *ignored*. How have we as a nation treated these fellow citizens?" 117 CONG. REC. at 45974 (emphasis added). Mr. Vanik described in no uncertain terms the "confinement without treatment," the "brutality," and the "unexplained deaths." *Id.* "But," he concluded, enactment of Section 504 would mean that Congress would "no longer tolerate the invisibility of the handicapped in America." *Id.*

Rising one month later on the floor of the United States Senate, Senator Humphrey stated:

> "Mr. President, I introduce . . . a bill to amend the Civil Rights Act of 1964 to insure equal opportunities for the handicapped by prohibiting needless discrimination in programs receiving Federal financial assistance. No longer dare we live with the hypocrisy that the promise of America should have one major exception: Millions of children, youth, and adults with mental or physical handicaps."

118 CONG. REC. at 525. "These people have *the right to live*," Senator Humphrey said, and "to know the dignity to which every human being is entitled." *Id.* (emphasis added). And Section 504 was designed to insure, among other equality guarantees, the "right to health," which, he said, was "fundamental." *Id.*

Leaving no room for dispute, Senator Percy followed Mr. Humphrey with a statement of cosponsorship, referenced a Concurrent Resolution he sponsored, and stated that Section 504 would "ensure that the handicapped will receive the basic rights to which every human being is entitled," rights that were "well

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of 1973." 45 C.F.R. Part 84, App. A, ¶3, 42 Fed. Reg. 22686 (1977). In *Consolidated Rail Corp. v. Darrone*, 104 S.Ct. 1248 (1984), the Court held that the 1978 amendment to Section 504 codified the HHS regulation. *See Alexander*, 105 S.Ct. at 722 n.24, 721 n.21, 724 n.27.

documented in the *Record* when the Concurrent Resolution was introduced." 118 CONG. REC. at 526. Senator Percy emphasized that Section 504 was to be the "legislative solution" to the problems outlined in the Concurrent Resolution. "These rights were clearly and forcefully spelled out in Senate Concurrent Resolution 52, . . . which I was privileged to co-sponsor. They are rights that must now be given the force of law. . . ." *Id.* at 11790. That Concurrent Resolution flatly stated:

> "*A mentally or physically handicapped person has the right to proper medical care and physical restoration* and to such education, training, rehabilitation, and guidance as will enable that person to develop his ability and potential to the fullest possible extent, *no matter how severe his or her degree of disability*."

S. Conc. Res. No. 52, 92d Cong., 1st Sess., 117 CONG. REC. 42294 (1971) (emphasis added).

Congress was well-aware that physicians and other professionals were often responsible for denigrating the abilities of severely handicapped people. Senator Humphrey stated that his bill was for "millions of handicapped children, youth, and adults who suffer the profound indignity and despair of *isolation, discrimination, and maltreatment*. It is essential that the right of these forgotten Americans to equal protection under the laws be effectively enforced through prohibiting their exclusion from services receiving Federal assistance." 118 CONG. REC. at 9495 (emphasis added). Describing the "categories of people who would be directly affected — children who are mentally retarded, physically handicapped" and condemning "the segregation of millions of Americans from society — suggesting a disturbing viewpoint that these people are not only forgotten but perhaps expendable," *id.*, Senator Humphrey requested and received unanimous consent to reprint in the *Record* a news series titled "The Expendables" which, the Senator stated, "la[id] before the public the true story of exclusion and inadequate concern experienced by hundreds of handicapped children." *Id.* The reports were laced with stinging criticisms of physicians, psychologists and other professionals who seriously devalued the

developmental potential and, indeed, the very lives of handicapped children. One example concerned a retarded child:

> "When Reuben first began working with an 11½-year-old-child we will call Jimmy, *doctors said the child had virtually no measurable intelligence and had a physical condition making it impossible for him to grasp and hold objects in his hands* . . . . Gradually, the attendant over a few days moved her hand away from the child's hand to his wrist. Already *the medical prediction was refuted* . . . It took another week to get Jimmy to feed himself independently without even the slightest pressure of the attendant's hand at his elbow."

118 CONG. REC. at 9499 (emphasis added). The report also documented the experience of parents who were told by pediatricians and others that their children's lives would be worthless:

> "They also spoke angrily about *pediatricians and purported experts in the field of retardation — the professionals who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents*. . . .
>
> "Mrs. Hosey remembers *a pediatrician* who called her child 'a moron,' and *a neurologist* who said, 'If you had eight hours a day and 20 years, maybe you could teach Stevie to feed himself.'
>
> "She also remembers with a touch of bitterness *other doctors who urged her and her husband to put Stevie in an institution and forget about him*. 'There was so much *willingness to eliminate the child*, because they did not consider him a productive member of society,' she said, 'but we only thought of him as our child and we did not feel guilty about him.' . . . [She felt] a deep anger at the system: A system which regularly has written off certain categories of handicapped children, their children, as hopeless."

118 CONG. REC. at 9500 (emphasis added). The "direct solution" to these "denial[s] of civil rights of millions of Americans," Senator Humphrey insisted (118 CONG. REC. at 9495), and Congress agreed, was the enactment of Section 504.

Section 504 was adopted to counter the view that they cannot learn or function. Senator Percy's statement on the Concurrent Resolution, like Representative Vanik's and Senator Humphrey's on the bill, emphasized that "it is intolerable to hide the handicapped" out of a belief that they are "hopelessly incapable" when Congress recognized and established with the enactment of Section 504 that "even the most severely handicapped" can learn and thrive. 118 CONG. REC. at 526.

III. SECTION 504 CALLS PHYSICIANS TO THEIR PROFESSIONAL SELVES.

Section 504 does not interfere with medical judgment. To the contrary, Section 504, if enforced, would call the medical profession to itself. By Section 504, Congress has prohibited disability-based exceptions to physicians' constant, fundamental commitment to sustain life. "[A] decision not to correct a life-threatening digestive problem because an infant has Downs Syndrome is not a bona fide medical judgment." *University Hospital*, 729 F.2d at 162 (Winter, *J.*, dissenting).

Allowing a handicapped baby to die violates Section 504 if it involves withholding not "extraordinary" measures but ordinary treatment that routinely would be performed if the child were not handicapped.[78] Refusal to perform lifesaving medical treatment because the child is handicapped is not a medical decision, but a decision based upon factors irrelevant to the child's medical needs.[79]

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78. "Extraordinary" treatment is defined by the American Medical Association as "the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent." Statement of the House of Delegates, December 4, 1973, *reported in* 227 J.A.M.A. 728 (1974). For the difference between extraordinary treatment and the treatment at issue here, see *supra* note 3.

79. Rachels, *Active and Passive Euthanasia*, 292 N. ENG. J. MED. 78, 80 (1975).

Physicians improperly present as "medical"" recommendations to parents of handicapped children nontreatment recommendations that in fact are based on the judgment that the child is better off dead than alive and handicapped.[80] Doctors know of parents' trust in their expertise[81] and of their vulnerability in the turmoil of the newborn period.[82] Physicians resort to medical nomenclature to disguise the nonmedical grounds of the recommendation: by labeling as "extraordinary" lifesaving treatment that is, in fact, quite ordinary[83] or by applying "selective criteria" for treatment that purport to be medical but in fact are based on other, nonmedical, values.[84]

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80. *See* the recommendation offered to parents by Dr. Judson Randolph, Surgeon-in-Chief at Children's Hospital of the National Medical Center in Washington, D.C.:

> "Your baby has two problems: one is correctible, the other, brain damage, is not correctible. Since I can only correct one of them and am unable to correct or alter in any way the other, I would prefer that you let me care for your baby, but without operating on him." *Surgical Decision — Is There a Choice?* in ROSS CONFERENCE ON PEDIATRIC RESEARCH, ETHICAL DILEMMAS IN CURRENT OBSTETRIC AND NEWBORN CARE 58 (1973). *See also* Randolph, *Consultant's Note*, 10 HOSP. ROUNDS, Sept., 1974, at 23.

81. *"At the end it is usually the doctor who has to decide the issue*. It is not only cruel to ask the parents whether they want their child to live or die, it is dishonest, because in the vast majority of cases, the parents are consciously or unconsciously influenced by the doctor's opinion." Shaw, *Dilemmas of Informed Consent in Children*, 289 N. ENG. J. MED. 885, 886 (1973) (emphasis added). *And see* Ingelfinger, *Bedside Ethics for the Hopeless Case*, 289 N. ENG. J. MED. 914 (1973) ("the onus of decision-making ultimately falls on the doctor in whose care the child has been put.")

82. Fost, *Counseling Families Who Have a Child With a Severe Congenital Anomaly*, 67 PEDIATRICS 321, 322-23 (1981).

83. *See, e.g.*, Shaw, *et al.*, *supra* note 3, at 594.

84. Dr. John Lorber, who pioneered the active treatment of spina bifida in the 1960s, found one problem with his results: "Improved techniques did not lead to fewer, but to more, handicapped children, because with the increased survival rate many more severely affected infants survive" causing "grave family, social, educational, financial and community problems." Lorber, *Spina Bifida Cystica: Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future*, 47 ARCH. OF DISEASE IN CHILDHOOD 854 (1972). For "selective criteria" used by physicians, *see* Stein, *et al.*, *Selection for Early Treatment in Myelomeningocele: A Retrospective Analysis of Various Selection*

Section 504, which secures to handicapped persons the "rights and liberties of normal people,"[85] requires precisely that physicians base their decisions *on* medical judgment, and that physicians extend the same respect to disabled people as customarily the profession does, and must, to all life.

CONCLUSION

The decision of the Court of Appeals should be reversed.

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NOTES *(Continued)*

Procedures, 54 PEDIATRICS 553 (1974) and Shurtleff, *et al.*, *Myelodysplasia: Decision for Death or Disability*, 291 N. ENG. J. MED. 1005 (1974), both stating that retardation is an appropriate reason for withholding surgery.

85. Compare the 1932 South Dakota government report, *supra* note 29.

APPENDIX A

COMPENDIUM OF THE MEDICAL LITERATURE OF THE ERA (1896-1920) DESCRIBING PHYSICIANS' PARTICIPATION IN THE GENERAL REGIME AND THEIR RATIONALE FOR ELIMINATING HANDICAPPED CHILDREN

Amici submit this brief historical note to describe the historical context in which the twentieth-century practice of allowing handicapped infants to perish at birth emerged in its present form and was pursued for the same reasons it is today.

The twentieth-century practice differs radically from other manifestations of infanticide in Western history. Before the twentieth century, victims of infanticide were not exclusively handicapped children; most commonly, they were nonhandicapped children who were unwanted for economic or social reasons.[1] Nor, before the twentieth century, did physicians sanction the practice in the guise of "medical judgment." Infanticide was practiced on a large scale in eighteenth and nineteenth century Europe because of extreme poverty, economic scarcity, and social forces that fostered illegitimacy but severely punished the unwed mother.[2] The 1890 edition of the *Encyclopedia Britannica* described the situation in late-nineteenth century England:

> "The modern crime of infanticide . . . is closely connected with illegitimacy in the class of farm and domestic servants. The crime is generally committed by the mother for the purpose of completing the concealment of her shame and, in other cases . . . to escape the burden of her child's support."[3]

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1. Radbill, *A History of Child Abuse and Infanticide*, in R.E. HELFER & C.H. KEMPE, eds., THE BATTERED CHILD 3 (1968).

2. M. PIERS, INFANTICIDE: PAST AND PRESIDENT 65 (1978); Williamson, *Infanticide: An Anthropological Analysis*, in M. KOHL, ed., INFANTICIDE AND THE VALUE OF LIFE 61, 69 (1978).

3. 13 ENCYCLOPEDIA BRITANNICA 3 (9th ed. 1890), *quoted in* D. BAKAN, SLAUGHTER OF THE INNOCENTS (1971).

By the end of the nineteenth century, a strong reaction against infanticide and other forms of child abuse had developed. In the United States, the child protection movement gained momentum from the formation of voluntary societies for the prevention of cruelty to children during the nineteenth century and culminated in the formation in 1912 of the Children's Bureau, which the federal government established to investigate and to report "upon all matters pertaining to the welfare of children and child life among all classes of our people."[4]

The movement to prevent child abuse at first did not distinguish between handicapped and nonhandicapped children. But in the first two decades of the twentieth century, the extreme devaluation and dehumanization of disabled persons that arose during that xenophobic and eugenist Era selectively affected the way handicapped infants were treated at birth. Until the late nineteenth century, physicians had neither opportunity nor inclination to engage in selective nontreatment of handicapped infants. Most infants were born at home; and before the development of asepsis, internal surgery was extraordinary.[5] Nor was the handicapped infant seen as a threat to the family or to society. Nineteenth century physicians' view of the infant's endowment at birth differed radically from that adopted by their twentieth-century counterpart under the influence of the determinist, hereditarian views widely held in that Era. Nineteenth century physicians thought that the infant remained malleable after birth and that its development could best be understood as a dynamic response to its environment. They made no absolute distinction between the innate and the acquired, but saw the relation of innate infirmity and achievement as "a protean affair of tendency and predisposition, not of discrete and unitary qualities."[6]

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4. Radbill, *supra* note 1; BAKAN, *supra* note 3, at 48-49.

5. M. VOGEL, THE INVENTION OF THE MODERN HOSPITAL 13, 60-61 (1980); G. ROSEN, THE STRUCTURE OF AMERICAN MEDICAL PRACTICE 1875-1914, at 44 (1983).

6. C.E. ROSENBERG, NO OTHER GODS: ON SCIENCE AND AMERICAN SOCIAL THOUGHT 27, 47 (1976). To the physician and others in the nineteenth

During the early twentieth century, many physicians adopted the determinist hereditarian and eugenicist attitudes of the Era and attempted to incorporate those attitudes into their practice of medicine. This adoption was not universal, however, for many physicians of the Era correctly perceived the fatal contradiction between their duty to heal and an ideology that preached that only the "fit" are worthy to be healed and that the physician's duty is to the race rather than to the patient.[7] Physicians and others of the Era understood that in practicing eugenics, the physician served *social* rather than therapeutic ends.[8]

During the first two decades of the twentieth century, eugenic ideas were widely discussed among physicians in medical journals, in scholarly papers, and at meetings of medical societies. Improvement of the race through regulation of marriage, sterilization of the unfit, and above all, the segregation of the feeble-minded were topics on which there was wide agreement that eugenic solutions were needed and that physicians had an important role to play in implementing them. Physicians who embraced eugenicism perhaps did so in their own self-interest[9] and emphasized the importance of their role in improving the race. "[I]f it is possible to perfect mankind," a surgeon of the U.S. Public Health Service wrote in 1915, "the means of doing

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century, deformity evoked a sense of man's fallen nature, a sense of the sin and inability borne by all men, "immanent yet not *quite* inevitable," susceptible to amelioration by habit, training, and moral activism. *Id.* at 38.

7. *See, e.g.*, Mason, *Some Thoughts on the Eugenic Movement*, 20 MED. REV. OF REVIEWS 146 (1914).

8. *Symposium on Euthanasia*, 19 MED. REV. OF REVIEWS 143, 152 (views of Professor R. Burton Opitz); Block, *The Social Aspects of the Bollinger Case*, 22 MED. REV. OF REVIEWS 122 (1916); *Euthanasia Again*, 88 MED. RECORD 925 (1915).

9. Hereditarian doctrines enabled physicians to reassure, to "find and intone an explanation" for what they could not cure, and thereby convert what could not be cured into a less threatening and more manageable reality. Such ideas were useful, therefore, in helping justify the social position of practicing physicians. C. E. ROSENBERG, *supra* note 6, at 50-51.

it will be in the medical profession."[10]

Editorials in medical journals urged that uniform laws on marriage be enacted to prevent the unfit from reproducing, and that the public be made aware of "the importance of fit and unfit matings";[11] doctors advocated that marriage be reformed and its traditions replaced by "laws based upon the broader needs of the race."[12] They admonished women to develop "a racial consciousness" and approach the choice of a husband as "a fundamental eugenic problem,"[13] for "the science of eugenics sets a new valuation upon the reproductive function."[14] Lest exhortation be insufficient, Chicago physicians participated in another incentive to "stimulate the physical improvement of the race": a baby show based on strict eugenic principles. The judges evaluated the young contestants for defects of the skin, bones, muscles and teeth, and even attempted to estimate the babies' I.Q.; the avowed purpose of the exhibition was "the stimulation of an ambition to beget and rear physically sound and normal offspring."[15]

Physicians seized upon the studies of the Jukes, the Kallikaks and other "defective strains" to prove that unfit marriages were "a crime against society, when as a result of them the unfit are born into the world."[16] If articles in leading medical journals

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10. Friedman, *Physical Basis for Moral and Mental Deficiencies*, 87 MED. RECORD 637 (1915).

11. *Some Problems in Genetics* (editorial), 20 MED. REV. OF REVIEWS 518 (1914); *Practical Eugenics*, 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 338 (1913).

12. Young, *Some of the Possibilities of Constructive Eugenics*, 20 MED. REV. OF REVIEWS 256 (1914).

13. *Women and Eugenics* (editorial), 21 MED. REV. OF REVIEWS 259 (1915).

14. *Eugenics and Religion*, 21 MED. REV. OF REVIEWS 200 (1915).

15. *Baby Shows and Eugenics*, 39 MED. STANDARD 227 (1916).

16. Satterthwaite, *Some Problems in Genetics*, 86 MED. RECORD 141 (1914); R. DUGDALE, THE JUKES: A STUDY IN CRIME, PAUPERISM, DISEASE AND HEREDITY (G.P. Putnam, 1877) (reprinted by Arno Press, 1970); H. GODDARD, THE KALLIKAK FAMILY: A STUDY IN THE HEREDITY OF FEEBLE-MINDEDNESS (Macmillan, 1912). *See* the favorable review of The Kallikak Family in the *Journal of the American Medical Association: A Natural*

are representative, physicians were heavily in favor of legislation mandating compulsory sterilization of retarded persons, despite their doubts about its constitutionality.[17] At a 1914 symposium on sterilization of the unfit, four out of five physicians who participated agreed that "defectives" should be sterilized.[18]

Support for the regime of state-imposed segregation of retarded persons that was established during the Era was, to judge from published comment, virtually unanimous. Writing in the leading medical journals of the day, physicians claimed that retarded persons were the "greatest social menace of the age,"[19] a "contamination that is polluting the stream of our social life,"[20] a "source of danger to the community."[21] "The moron is ubiquitous, and has been so, but his ability to harm has only recently been emphasized."[22] The editor of the *Journal of the American Medical Association* lamented that the "man in the street" did not yet realize the economic and social problems connected with the feeble-minded and that "this class is increasing enormously in all civilized countries."[23]

Typical of medical opinion of the day are the views of a physician in Kansas City, who, claiming that "segregation of the feeble-minded is advocated by medical authority the world over," argued that the feeble-minded must not be allowed to

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Object-Lesson in Heredity, 59 J.A.M.A. 1545 (1912). The intentionally distorted methodologies and survey results of Dr. Goddard and others are taken apart painstakingly and devastatingly in J.D. SMITH, MINDS MADE FEEBLE: THE MYTH AND LEGACY OF THE KALLIKAKS (1985).

17. *See, e.g., Eugenics and the Limitation of Offspring*, 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 266 (1913); Orton, *The Procreative Regulation of Defectives and Delinquents*, 58 J.A.M.A. 2021 (1912).

18. Robinson (ed.), *A Symposium on Sterilization of the Unfit*, 20 MED. REV. OF REVIEWS 13 (1914).

19. *How Far Shall the Public School System Care for the Feeble-Minded?* 58 J.A.M.A. 1631, 1632 (1912).

20. *New Jersey's Rational Approach to the Problems of Degeneracy*, 20 MED. REV. OF REVIEWS 71 (1914).

21. *Care of the Feeble-Minded* (editorial), 89 MED. RECORD 827, 828 (1916).

22. Wildman, *Mental Defectives: Their Importance*, 88 MED. RECORD 1093 (1915).

23. *The Menace of the Feeble-Minded*, 62 J.A.M.A. 938 (1914).

remain in the public schools, "contaminating the rest of the school children by their . . . psychic insufficiency, moral indifference, and uncontrollable impulses."[24] Physicians advocated that all children be examined when they first entered school, so that those found to be feeble-minded could be excluded and segregated in institutions.[25] Once institutionalized, these children were to be segregated for life: To give the feeble-minded training and then "turn them loose on the community" would be "a moral and economic blunder."[26]

Physicians, both in the public health service and in private practice, played an important role in identifying candidates for institutionalization. Doctors were eager to arrogate this role to themselves, and feared that IQ tests would render their participation less essential. Physicians urged that retardation was "fundamentally a medical problem,"[27] and that physicians were best suited to diagnose it.[28] Because of the grave danger posed by the borderline retarded person,[29] an incorrect diagnosis of retardation could result in "untold danger"[30] to society. Physicians argued that it was often impossible for the lay person to make a diagnosis of retardation by inspection alone and that doctors were uniquely qualified to make the determination because of their expertise in the physical manifestations of inferior mentality (the so-called "stigmata of degeneration"): "It is only by close

24. Punton, *The Segregation and Treatment of the Feeble-minded*, 222 ILL. MED. J. 299 (1912).

25. *How Far Shall the Public School System Care For the Feeble-Minded?* *supra* note 19, at 1632 (statements of Drs. E. Bosworth McCready & W.G. Schauffler).

26. *The Feeble-Minded in Ohio*, 64 J.A.M.A. 1681 (1915). *See also* Spaulding, *Our Criminal Problem From The Standpoint of Classification and Segregation*, 173 BOSTON MED. & SURG. J. 527 (1915); Kendall, What Are We Doing and What Should We Do For the Feebleminded? (Paper given before the annual meeting of the Medical Association of the Southwest), *abstracted in* 65 J.A.M.A. 1845 (1915).

27. Schlapp & Paulsen, *Report on 10,000 Cases from the Clearinghouse for Mental Defectives*, 93 MED. RECORD 269 (1918).

28. Schlapp, *The Clearing House for Mental Defectives*, 88 MED. RECORD 299, 300 (1915).

29. *Care of the Feeble-Minded*, 89 MED. RECORD 827, 828 (1916).

30. Schlapp & Paulsen, *supra* note 27, at 301.

attention to details of physical makeup that the suspicion may be aroused that the subject is abnormal."[31]

Physicians recommended that medical personnel be given the authority to designate who should be committed. For example, in a report adopted by the New York Psychiatric Association, a committee of three physicians recommended that in each community a local health official be designated to act as "Medical Supervisor of the Mentally Defective," to arrange for the examination and placement of all persons brought to his attention who might be retarded.[32] In New York City, the trustees of the Post-Graduate Hospital set up a Clearing House for Mental Defectives staffed by ten physicians and four psychologists, charged with "scientific detention, diagnosis, registration of and research into mental deficiency." Its purpose was "to deal with the problem presented by the mentally unfit members of the community, in order that the most dangerous of them may be eliminated from among the possibilities of menace" and to ensure their "proper segregation."[33]

The private physician also played an important role in detecting feeble-minded persons and convincing their families of the need for segregation. A common lament in the medical literature of the Era was the difficulty physicians encountered in persuading parents to allow their children to be institutionalized. For example, Theodore Diller, a Pittsburgh physician, reported in a paper read before the Chicago Medical Society and the Academy of Medicine in Cleveland:

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31. Wildman, *supra* note 22, at 1093.

32. *Outline of a State Policy for Dealing With Mental Deficiency*, 87 MED. RECORD 665, 667 (1915). Two of the five members of the commission appointed in 1914 by the governor of New York to investigate the "problem" of the "feeble-minded" in that state were physicians and professors of medicine at leading medical schools in the state. 86 MED. RECORD 208 (1914).

33. Schlapp, *supra* note 28; Schlapp & Paulsen, *supra* note 27. Physicians were also assigned by school officials to examine and determine the status of children referred by teachers as suspected of having a mental or physical defect. *See, e.g.*, Krause, *The Necessity for Parental Cooperation in the Examination of Mental Defectives*, 86 MED. RECORD 337 (1914).

> "I have had numerous experiences where I have strongly advised that a feeble-minded child be sent to the institution at Polk for the good of the child, for the good of the parent, and for the good of the public, and where the parents have declined to take the step. Also, I have had the experience of seeing feeble-minded persons taken to an institution and brought away from it against the advice of the superintendent of the institution and myself. In short, this very important and fundamental question of admission or discharge from institutions for the feeble-minded is decided by the parents of the feeble-minded; and the institution or family physician have only advisory powers. This is obviously wrong and should be corrected."[34]

In a similar vein, a physician from Kansas City decried that feeble-minded children were allowed to "stay in school and mix with the other pupils" because of the "pride, indifference, financial and social standing or political pull" of their parents and complained,

> "Many such are referred to the family physician for relief, but what to do for them at once propounds the most difficult medical, legal, sociological problem of this age, because of the serious lack of state or civic provision, as well as the legal complications involved in enforcing their appropriate custody and control. Many parents refuse absolutely to cooperate with the authorities, hence a large number of such defective children are forced back on society and allowed to go more or less unrestrained."[35]

Nevertheless, commitment to eugenicism was not universal among the medical profession. Some physicians argued that the healer's traditional role was better served by searching out and

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34. Diller, *Menace to the Public by Feeble-minded Persons Living Outside Institutions*, 11 CLEVELAND MED. J. 420 (1912).

35. Punton, *supra* note 24, at 302. *See also* Bernstein, The Various Phases of Feeblemindedness and the Stigmata of Degeneration, Physical Types, etc. (Paper presented before the 11th Annual Meeting of the Medical Society of the State of New York), *abstracted in* 91 MED. RECORD 876 (1917).

alleviating possible physiological causes of retardation[36] than by rounding up retarded persons for segregation; others argued that marriage and the family should not be reduced to "breeding experiments"[37] and attacked the shoddy methodology of the geneology studies.[38] Indeed, physicians on both sides of the eugenics issue understood that there was an irreducible conflict between the healing function of the medical profession and the eugenicist's desire to improve the race. Eugenicists told physicians that it was their own "humanitarianism" that, by interfering with the survival of the fittest, had plunged the race into its present state of decline.[39] Physicians admitted the allegation. As one commentator, reporting for a medical journal on the first world Eugenic Conference held in London in July 1913, put it, in terms addressed to both physicians and parents:

> "Unfortunately, we are at present degenerating rather than progressing, because with our modern ideas of sanitation, good housing, proper medical treatment and the increase of comfort, we preserve inferior types which would have never reached maturity under the more severe conditions of even a century ago. The weeding out process which obtains among wild animals and preserves a highly vigorous type amongst them, no longer applies to civilized man and the more our sympathies go towards the helpless and diseased, the worse it is for the race. Let us therefore show interest in the eugenic movement; to do this, however, we must put aside our sympathies for the unfit. Women must help the men and, however repulsive it is to our refined feelings, we

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36. *Feeblemindedness as a Constitutional Anomaly*, 62 J.A.M.A. 304 (1914).

37. Groszmann, *Sane Eugenics*, 20 MED. REV. OF REVIEWS 638, 639 (1914).

38. *Id.* at 640. *See also Eugenics Laws*, 20 MED REV. OF REVIEWS 405, 406 (1914).

39. *See, e.g., The Problem of the Feeble-Minded* (editorial), 58 J.A.M.A. 785 (1912) (reporting eugenicist Charles Davenport's views).

must learn to understand that just as . . . animal experimentation entails some suffering, so the eugenic movement will mean severe repressive measures before it becomes effective."[40]

The issue whether handicapped infants should be allowed to die at birth posed the conflict between the healer's mission and the eugenicist's dream of a superior race most sharply. Physicians seldom discussed the issue in public, no doubt because they understood that such practices could carry both criminal and civil penalties.[41] In 1915, however, the highly-publicized case of John Bollinger, a handicapped infant born at the German-American Hospital in Chicago in 1915, whose life Dr. Harry Haiselden, Chief of Staff at the hospital, refused to save by performing surgery to correct an imperforate anus, thrust the issue into public attention.[42]

Two round-table discussions held shortly after the Bollinger incident illustrate the terms in which the conflict was posed between the physician's lifesaving duty and the eugenicist's perception of his duty to the race. At a "Symposium on Obstetrical Abnormalities" sponsored by the *Medical Review of Reviews*, a group of prominent obstetricians (all of whom had faculty appointments at university medical schools and medical colleges) discussed the question whether, when a severely handicapped baby is delivered, the obstetrician should neglect to tie the umbilical cord.[43] Partly because of the nature of the question (as several participants pointed out, a newborn will not usually die

40. Mason, *supra* note 7, at 148.

41. The *Journal of the American Medical Association* carried no discussion of the Bollinger case (*see infra* notes 42-63 and accompanying text) or any of the other widely-discussed cases of handicapped infants denied medical treatment during the Era. For the legal views of the Era, *see Is it a Crime For A Physician To Cause a Parent to Withhold a Life-Saving Operation or Remedy From a Dying Child?* 81 CENTRAL L.J. 379 (1915) (answering the question in the affirmative); *Editorial Comment*, 22 CASE & COMMENT 680 (accord).

42. *See* text of Brief, *supra* at pp. 9-10. For a general discussion of the Bollinger case, *see* S.L. Kuepper, Euthanasia in America (Rutgers Univ. diss. 1981), at 68-83.

43. *A Symposium on Obstetrical Abnormalities*, 22 MED. REV. OF REVIEWS 95 (1916).

from an untied umbilical cord) and their recognition that such an act would be unlawful, most responses were negative. Many participants echoed the statement of a professor at the University of Pittsburgh that such an act would be simply "contrary to medical ethics and all other forms of ethics."[44] Others added that "however much such an act might be in the interest of society or the development of the ideal,"[45] it would be an abuse of the physician's duty to heal.[46] Several respondents voiced the typically nineteenth-century attitude that a person's endowment could not be judged at birth[47] and that the presence of deformity should "stimulate . . . the medical investigator to find a means of restoring such individuals to health."[48] Other participants, however, stated that abnormalities are "a detriment to society" and that it is "humane to cut off their future suffering by one means or another, preferably 'forgetting' to tie the cord.[49] Another responded with regret that

> "the physician has no right under the laws, as they exist, to terminate the life of a new born infant . . . for no one shall be deprived of life — without due process of law. There exists at the present time no process of law by which this, however desirable, can be accomplished."[50]

He added, "The question is really an economic one and the ethical questions involved ultimately arise from economic facts," and suggested that the matter might be proposed for legislative discussion, but, until then, it was necessarily "academic."[51]

The round table on "The Defective Child" sponsored by the *Medical Standard*[52] evoked a different discussion. The journal invited not only Dr. Haiselden himself but also Dr. Henry H.

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44. *Id.* at 97 (statement of Dr. Walter L. Croll).
45. *Id.* at 100 (statement of Dr. Walter P. Manton).
46. *Id.* at 99 (statement of Dr. Nathan Jenks).
47. *Id.* at 100 (statement of Dr. Henry J.E. Newman).
48. *Id.* at 102 (statement of Dr. Herbert M. Stone).
49. *Id.* at 102 (statement of Dr. William C. Rausch); *id.* at 100 (statement of Dr. David Monash).
50. *Id.* at 97 (statement of Dr. Edward M. Colie, Jr.).
51. *Id.*
52. 39 MED. STANDARD 35 (1916).

Goddard, author of numerous works on eugenics and the dangers of retarded persons to society. A majority of the participants advocated the eugenic solution to the problem of the "defective" infant. Dr. Haiselden echoed nearly all the common sentiments of the eugenicist wing of the medical profession recited above. He declared himself willing to sacrifice the physician's duty to heal for the progress of the race. "The whole human race is deteriorating," he stated, "because of false ideas that saving human life is absolutely sacred."

> "We are bending our best energies to saving life which will in no way add to our prestige as a nation of eugenists or even of advanced ideas. In other words, by our hot house methods we are keeping alive disease which should be destroyed and would be destroyed if it were not for extraordinary efforts made to preserve it."

He summarized his views on the care of the defective child as follows:

> "The physician owes a duty to humanity, to the parents, and to himself to use no means other than supplying the necessary warmth and food to keep the child alive. Progress will in the near future . . . demand that he go one step farther and neglect to tie the cord."

As for "defective" children who survive, Dr. Haiselden thought they should be "cared for by the state in an institution and not be permitted to be at large. Such individuals are . . . a constant pain to their parents and relatives." Dr. Haiselden urged that defectives be sterilized immediately after they are placed in institutions, and went on to express his hope that "if all defectives were placed in institutions and the institutions were used to the best advantage of the eugenists," those who subscribed to his beliefs would be able to secure data that would convince the general public of the value of eugenics. He lamented that while "[t]hose of scientific training are readily convinced . . . the general public is inclined to hesitate."[53]

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53. *Id.* at 35-36.

Dr. Rose Alexander Bowers of Laporte, Indiana argued strongly that the law of "survival of the fittest" be allowed to govern the care of handicapped newborns and that the physician in charge should be allowed to decide the merits of each case. "As we weed out the undesirable growths in a garden, in the same manner we should prevent and destroy the defective seedlings in the human garden." The attitude of the state toward those who survive should be "one of suppression, no matter whether he be a mental or physical abnormal." Mental defectives needed to be sterilized and segregated for their own protection and that of society, "which is never edified by the sight of an idiot."[54]

Dr. Frederick H. Robinson of New York City stated that the lives of "imbeciles" should not be saved *even where* the parents "in sound mind and good economic position" demand it. "The physician's duty to humanity demands that he limit, not increase, the number of defectives" for "if present conditions continue unabated, the whole nation will be lowered in its vitality and will not be able to keep up the march of progress with other nations."

> "[T]he defective child is a burden and takes away what rightfully belongs to normal human beings. No special attempt should be made at any time during its life to preserve the defective. A physician removes a rotten part or diseased condition in a patient. In the same way, the state should remove the hopelessly defective, so that the rest may thrive better."[55]

In all, seven out of the ten participants in the symposium agreed that death was an acceptable solution in the case of the defective infant. The round table closed with a statement by Dr. Goddard that the physician is under an affirmative obligation *not* to save the defective child's life, for "part of the physician's moral obligation is to the community and he has no right to bring into the community a being that will always be a burden and a source of

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54. *Id.* at 36-37.
55. *Id.* at 37-38.

unhappiness and inefficiency."[56] Approximately three years earlier, Dr. Goddard had hinted at these views when he spoke to the Third Annual Meeting of the American Association for the Study and Prevention of Infant Mortality. Dr. Goddard suggested, in his remarks to the Association, that reduced infant mortality would have dangerous social consequences if it led to the survival of retarded persons:

> "A surprisingly large percentage of people are of such low mentality that they are incapable of living a normal life. They do not have enough judgment or intelligence to do those things that make for happiness and prosperity. . . . a large percentage of these children, if they live and grow up, will be mentally deficient, will always be a burden on society and more or less a burden to themselves. Therefore, when we keep these people alive, we are simply laying up trouble for ourselves and for these same children."

Recognizing that his audiences were committed to saving life and therefore probably would not accept elimination of the "unfit" at birth, Dr. Goddard offered a tradeoff: Eugenicists would accept, however reluctantly, that all severely disabled people not be eliminated at birth in exchange for adoption of the remainder of the eugenicists' program — sterilization and segregation — by those whose humanitarianism would not allow them to condone infanticide:

> "If our humanity will not allow us to let these children die as infants, our humanity certainly does not prevent us from insisting that they shall be the last of their race."[57]

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56. *Id.* at 41-42.

57. *Reported in* 59 J.A.M.A. 1645 (1912). A physician and editor of a medical journal of the Era also suggested that the eugenicist and the healer "could come to an agreement" on the subject of elimination of the unfit. Eugenicists would agree not to kill off the "weak and puny" if healers would agree to do their best "to prevent the bringing forth of undesirable specimens." Robinson, *Eugenics and the Limitation of Offspring* (editorial), 16 MEDICO-PHARMACEUTICAL CRITIC & GUIDE 266, 269 (1913). Dr. Robinson had already professed his sympathy for involuntary euthanasia of the "gibbering idiot" who

In other discussion of the incident, both supporters and opponents of Dr. Haiselden's handling of the Bollinger case agreed that the decision to let the child die was not a medical but a sociological judgment. An editorial in the *Medical Record* criticized Dr. Haiselden and suggested that if the child's *medical* condition had warranted nontreatment, nontreatment might have been justified. However, the reason he gave to the world and Cook County for his abstention was "not a good one" because it lay outside the scope of medical judgment: "A doctor cannot say that an infant who is physically defective cannot grow up to be a useful member of society."[58] In an article in the *Medical Review of Reviews*, a noted journalist and social activist praised Dr. Haiselden precisely *because* he had refused to restrict himself to medical considerations in deciding whether or not to treat the child.

> "[T]he time is here when the progressive wing of the medical profession . . . itself takes the position that the opinions of economists, sociologists, social workers and social reformers generally are, if anything, more important in the consideration of such a problem as this than the opinions of mere doctors."

The author praised Haiselden for placing the good of the race ahead of the good of the individual. "It is good . . . when a Dr. Haiselden arises among us and rekindles that faith in the ultimate socializing of the individual for the greater glory of the race."[59] Finally, an editorial in the *Boston Medical and Surgical Journal* that took no position on the matter related the interest aroused by the Bollinger case to the "ever-increasing interest of the public in problems centering around the control of the defective element in society."[60]

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is "a great burden to those around him," a "curse and humiliation" to his relatives, but unfortunately, "prefers life to death." *Euthanasia* (editorial), *id.* at 85 (1913).

58. 88 MED. RECORD 925 (1915).

59. Block, *supra* note 8, at 122.

60. *Modern Euthanasia*, 173 BOSTON MED. & SURG. J. 1008 (1915).

At the Round Table on the Defective Child, Dr. Haiselden had expressed the hope that physicians would go "one step farther" than denial of life-saving medical treatment and "neglect to tie the cord." Two years later, Dr. Haiselden did just that to a baby girl born with microcephaly.[61] The lesson of the latter case, he proclaimed, was that "physicians will more and more take it upon themselves to decide at birth the fitness or unfitness of a child to live."[62] That this child's death, and that of others killed in that year, passed virtually without comment in the medical journals or the popular press[63] may be an index of its acceptability once the foundation of the regime of segregation had been more securely laid.

The entire purpose of the regime was elimination of handicapped persons — whether by segregating them from the rest of society, preventing them from propagating, or destroying their lives at birth. Thus it can be no surprise that physicians who participated in the regime, and whose attitudes were shaped by it, should choose to abandon the role of healer for the sake of eliminating the "unfit" at birth.

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61. Haiselden, *Regarding the Meter Baby of Chicago*, 23 MED. REV. OF REVIEWS 697 (1917). In fact, Dr. Haiselden went one step farther even than that; he first ligated the cord to allow his colleagues to inspect the baby, then untied it and allowed the baby to bleed to death from the navel. *Id*.

62. *Id*.

63. Kuepper, *supra* note 42, at 82.

APPENDIX B
COMPILATION OF CONGRESSIONAL HEARINGS AND REPORTS, 1972-1975

On the Rehabilitation Act of 1973 and the succeeding Rehabilitation Amendments of 1974, see during the 92d Cong., 2d Sess. (1972): *Vocational Rehabilitation Services for the Handicapped*, Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Rehabilitation Act of 1972*, Parts 1 & 2, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 92-928; S. REP. NO. 92-1135; H. CONF. REP. NO. 92-1581; during the 93d Cong., 1st Sess (1973): *Vocational Rehabilitation Services*, Parts 1 & 2, Oversight Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Rehabilitation Act, 1973*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 93-244; S. REP. NO. 93-318; H. CONF. REP. NO. 93-500; during the 93d Cong., 2d Sess. (1974): *Rehabilitation Act Amendments of 1974*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. REP. NO. 93-1048; S. REP. NO. 93-1139; H. CONF. REP. NO. 93-1457.

On the Developmentally Disabled Assistance and Bill of Rights Act of 1975, see during the 93d Cong., 1st Sess. (1973): *Developmental Disabilities Act Extension and Rights of Mentally Retarded, 1973*, Hearings on S. 427 and S. 458 Before the Subcomm. on Labor and Public Welfare; during the 93d Cong. 2d Sess. (1973): *Developmentally Disabled Assistance and Bill of Rights Act, 1974*, Hearings on S. 3378 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; *Health Services and Health Revenue Sharing*, Hearings on H. R. 11511, 11518, 11845 and 12892 Before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce, Part 2; S. REP. NO. 93-1169; H. R. REP. NO. 93-1127; during the 94th Cong., 1st Sess. (1975): *Developmentally Disabled Assistance and Bill of Rights Act,*

1975, Hearings on S. 462 Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; *Health Services Programs*, Hearings on H. R. 2954 Before the Subcomm. on Public Health and Environment of the House Comm. on Interstate and Foreign Commerce; S. REP. NO. 94-160, see especially the parts at 26-39, "Forces Behind Institutionalization and Deinstitutionalization" and "Bill of Rights for the Mentally Retarded and Other Individuals with Developmental Disabilities," which accompany Title II, the Bill of Rights; H. R. REP. NO. 94-58; H. CONF. REP. NO. 94-473.

On the Education for All Handicapped Children Act of 1975 and its predecessor Elementary and Secondary Education Amendments of 1974, see during the 93d Cong., 1st Sess. (1973): *Education of the Handicapped Act Amendments*, Hearings Before the Select Subcomm. on Education of the House Comm. On Education and Labor; *Education for the Handicapped, 1973*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; during the 93d Cong., 2d Sess. (1974): *Financial Assistance for Improved Educational Services for Handicapped Children*, Hearings Before the Select Subcomm. on Education of the House Comm. on Education and Labor; *Education for All Handicapped Children, 1973-74*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare, Parts 1-4; H. R. REP. NO. 93-805; S. REP. NO. 93-763; H. CONF. REP. NO. 93-1211; during the 94th Cong., 1st Sess. (1975): *Education for all Handicapped Children, 1975*, Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Public Welfare; H. R. REP. NO. 94-332; S. REP. NO. 94-168; H. CONF. REP. NO. 94-664; S. CONF. REP. NO. 94-455.

On the White House Conference on Handicapped Individuals Act, see S. REP. NO. 92-1080, 92d Cong., 2d Sess. (1972); S. REP. NO. 93-319, 93d Cong., 1st Sess. (1973); S. REP. NO. 93-1139, 93d Cong., 2d Sess. 31-40 (1974).